

From: Amber Millen
Sent: Thu, 17 Oct 2019 14:49:37 -0700
To: Satish Raj; Chelimsky, Gisela; Steven Vernino; Cheshire, William P.; Singer, Wolfgang; Shibao, Cyndya; Snapper, Howard; Victoria Claydon; Goldstein, David (NIH/NINDS) [E]; Lucy Norcliffe-Kaufmann; Vera-Ellen Lucci; Sabharwal, Rasna
Subject: AAS minutes from October 16
Attachments: AAS BoD Meeting Minutes 2019Oct16.pdf

Hi all,

Here are the minutes from yesterday's Board call.

Cheers,
Amber

Amber Millen | Executive Director, American Autonomic Society
9500 Gilman Drive | BSB 5006, MC 0629 | La Jolla, CA 92093-0629 | USA
E: amber@americanautonomicsociety.org | T: (858) 534-3865 | F: (858) 534-1445
www.americanautonomicsociety.org | Follow us: @AASAutonomic



American Autonomic Society Board of Directors – Meeting Minutes
Wednesday, October 16, 2019 (5pm EDT; 2pm PDT)

(b)(4)



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(b)(4)



From: amber@americanautonomicsociety.org
Sent: Wed, 16 Oct 2019 13:00:00 -0700
To: Cheshire, William P.; Satish Raj; Norcliffe-Kaufmann, Lucy; Shibao, Cyndya; Chelimsky, Gisela; Singer, Wolfgang; Goldstein, David (NIH/NINDS) [E]; Steven Vernino <Steven.; Howard Snapper; Victoria Claydon; Sabharwal, Rasna; Vera-Ellen Lucci
Subject: Update: AAS BOARD MONTHLY CONFERENCE CALL
Attachments: AAS BoD Meeting Agenda 2019Oct16.docx

See attached agenda for meeting today...

AAS BOARD MONTHLY CONFERENCE CALL

3rd Wednesday of the month (2 pm Pacific / 3 pm Mountain / 4 pm Central / 5 pm Eastern)

US: (b)(6)

Canada: (b)(6)

Meeting ID: (b)(6)

International numbers available: (b)(6)

Amber Millen, Executive Director
American Autonomic Society
9500 Gilman Drive, BSB 5006, MC 0629
La Jolla, CA 92093-0629 USA
Office (858) 534-3865, Fax (858) 534-1445
Email: amber@americanautonomicsociety.org
Website: <http://americanautonomicsociety.org/>

American Autonomic Society Board of Directors – Meeting Agenda
Wednesday, October 16, 2019 (5pm EDT; 2pm PDT)

(b)(4)



American Autonomic Society Board of Directors – Meeting Agenda
Wednesday, October 16, 2019 (5pm EDT; 2pm PDT)

(b)(4)



From: Kaufmann, Horacio
Sent: Mon, 14 Oct 2019 22:06:15 +0000
To: Satish Raj
Cc: Chapleau, Mark; Low, Phillip A., M.D.; Italo Biaggioni; Thomas Chelimsky; Gisela Chelimsky; Cheshire, William P., M.D.; Roy Freeman; Benarroch, Eduardo E., M.D.; Felicia Axelrod; Goldstein, David (NIH/NINDS) [E]; Joyner, Michael J., M.D.; Norcliffe-Kaufmann, Lucy; David Robertson; Rose Robertson; Cyndya Shibao; Singer, Wolfgang, M.D.; Steven Vernino; Alex Barboi; Amber Millen; Chris Gibbons
Subject: Re: [External] AAS HPV Vaccine Statement

Excellent response.
Mark has a point regarding clinical care. Easily solved by saying most of the authors.
Could also be removed of course.
Great job.
Thanks so much to the writers.
H

Sent from my iPhone

On Oct 14, 2019, at 5:51 PM, Satish Raj <satish.raj@ucalgary.ca> wrote:

Mark,

We will remove the final paragraph.

We will look at the bullet point that you mention.

Thanks,

Satish

From: Chapleau, Mark <mark-chapleau@uiowa.edu>
Sent: October 14, 2019 9:18 AM
To: Satish Raj <satish.raj@ucalgary.ca>; Low, Phillip A., M.D. <low@mayo.edu>; Italo Biaggioni <italo.biaggioni@vumc.org>; Thomas Chelimsky <tchelimsky@mcw.edu>; Gisela Chelimsky <gchelimsky@mcw.edu>; Cheshire, William P., M.D. <cheshire@mayo.edu>; Roy Freeman <rffreeman@bidmc.harvard.edu>; Benarroch, Eduardo E., M.D. <benarroch@mayo.edu>; Felicia Axelrod <Faxelrod@rcn.com>; David Goldstein <goldsteind@ninds.nih.gov>; Joyner, Michael J., M.D. <joyner.michael@mayo.edu>; Horacio Kaufmann <Horacio.Kaufmann@nyumc.org>; Lucy Kaufmann <norcll01@nyumc.org>; David Robertson <david.robertson@vanderbilt.edu>; Rose Robertson <rosemarie.robertson@heart.org>; Cyndya Shibao <cyndya.shibao@vumc.org>; Singer, Wolfgang, M.D. <Singer.Wolfgang@mayo.edu>; Steven Vernino <Steven.Vernino@UTSouthwestern.edu>
Cc: Alex Barboi <ABarboi@northshore.org>; Amber Millen <amber@americanautonomicsociety.org>; Chris Gibbons <cgibbons@bidmc.harvard.edu>
Subject: RE: [External] AAS HPV Vaccine Statement

Well written response. I am willing to co-author. I agree with Wolfgang's suggestion to delete the last paragraph which has a couple of issues.

The first sentence in the final paragraph also states that "all of the authors care for patients with POTS". This statement doesn't apply to me, so if the wording stays, please remove my name from the author list.

Minor:

In paragraph 4, line 5, consider "...appropriate method to assess the risk of vaccination", or something similar.

The last bullet point sentence would benefit from revision.

Mark

From: Satish Raj <satish.raj@ucalgary.ca>

Sent: Sunday, October 13, 2019 4:28 PM

To: Low, Phillip A., M.D. <low@mayo.edu>; Italo Biaggioni <italo.biaggioni@vumc.org>; Chapleau, Mark <mark-chapleau@uiowa.edu>; Thomas Chelimsky <tchelimsky@mcw.edu>; Gisela Chelimsky <gchelimsky@mcw.edu>; Cheshire, William P., M.D. <cheshire@mayo.edu>; Roy Freeman <rffreeman@bidmc.harvard.edu>; Benarroch, Eduardo E., M.D. <benarroch@mayo.edu>; Felicia Axelrod <Faxelrod@rcn.com>; David Goldstein <goldsteind@ninds.nih.gov>; Joyner, Michael J., M.D. <joyner.michael@mayo.edu>; Horacio Kaufmann <Horacio.Kaufmann@nyumc.org>; Lucy Kaufmann <norcll01@nyumc.org>; David Robertson <david.robertson@vanderbilt.edu>; Rose Robertson <rosemarie.robertson@heart.org>; Cyndya Shibao <cyndya.shibao@vumc.org>; Singer, Wolfgang, M.D. <Singer.Wolfgang@mayo.edu>; Steven Vernino <Steven.Vernino@UTSouthwestern.edu>

Cc: Alex Barboi <ABarboi@northshore.org>; Amber Millen <amber@americanautonomicsociety.org>; Chris Gibbons <cggibbons@bidmc.harvard.edu>

Subject: [External] AAS HPV Vaccine Statement

Colleagues,

Our AAS HPV Vaccine Statement has been published online in CAR, and the Autonomic Neurosciences Publication is coming.

There has been a Letter to the Editor about our article that has been accepted by CAR. We have been asked to respond.

Please find attached the letter from Svetlana and the response that Alex, Chris and I have crafted.

Please look this over and confirm that you are willing to co-author the response. Please also email if there are significant changes to our response that you think are needed.

There is some time sensitivity to this. Please try to return this to us within 72 hours.

If I do not hear from you, I will assume you are OK with this response (but would prefer to hear this from you).

Thank you,

Satish

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From: Chelimsky, Gisela
Sent: Mon, 14 Oct 2019 20:05:13 +0000
To: Low, Phillip A., M.D.; Chelimsky, Thomas; Biaggioni, Italo; Singer, Wolfgang, M.D.; 'Satish Raj'; Mark Chapleau; Cheshire, William P., M.D.; Roy Freeman; Benarroch, Eduardo E., M.D.; Felicia Axelrod; Goldstein, David (NIH/NINDS) [E]; Joyner, Michael J., M.D.; Horacio Kaufmann; Lucy Kaufmann; David Robertson; Rose Robertson; Shibao, Cyndya; Steven Vernino
Cc: Alex Barboi; Amber Millen; Chris Gibbons
Subject: RE: AAS HPV Vaccine Statement

I fully agree. Gisela

From: Low, Phillip A., M.D. <low@mayo.edu>
Sent: Monday, October 14, 2019 7:08 AM
To: Chelimsky, Thomas <tchelimsky@mcw.edu>; Biaggioni, Italo <italo.biaggioni@vumc.org>; Singer, Wolfgang, M.D. <Singer.Wolfgang@mayo.edu>; 'Satish Raj' <satish.raj@ucalgary.ca>; Mark Chapleau <mark-chapleau@uiowa.edu>; Chelimsky, Gisela <gchelimsky@mcw.edu>; Cheshire, William P., M.D. <cheshire@mayo.edu>; Roy Freeman <rffreeman@bidmc.harvard.edu>; Benarroch, Eduardo E., M.D. <benarroch@mayo.edu>; Felicia Axelrod <Faxelrod@rcn.com>; David Goldstein <goldsteind@ninds.nih.gov>; Joyner, Michael J., M.D. <joyner.michael@mayo.edu>; Horacio Kaufmann <Horacio.Kaufmann@nyumc.org>; Lucy Kaufmann <norcll01@nyumc.org>; David Robertson <david.robertson@vanderbilt.edu>; Rose Robertson <rosemarie.robertson@heart.org>; Shibao, Cyndya <cyndya.shibao@vumc.org>; Steven Vernino <Steven.Vernino@UTSouthwestern.edu>
Cc: Alex Barboi <ABarboi@northshore.org>; Amber Millen <amber@americanautonomicsociety.org>; Chris Gibbons <cgibbons@bidmc.harvard.edu>
Subject: RE: AAS HPV Vaccine Statement

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I fully agree.
Phillip

From: Chelimsky, Thomas [<mailto:tchelimsky@mcw.edu>]
Sent: Sunday, October 13, 2019 8:18 PM
To: Biaggioni, Italo; Singer, Wolfgang, M.D.; 'Satish Raj'; Low, Phillip A., M.D.; Mark Chapleau; Chelimsky, Gisela; Cheshire, William P., M.D.; Roy Freeman; Benarroch, Eduardo E., M.D.; Felicia Axelrod; David Goldstein; Joyner, Michael J., M.D.; Horacio Kaufmann; Lucy Kaufmann; David Robertson; Rose Robertson; Shibao, Cyndya; Steven Vernino
Cc: Alex Barboi; Amber Millen; Chris Gibbons
Subject: [EXTERNAL] Re: AAS HPV Vaccine Statement

Agree 100%, nice response. Would move second paragraph to be concluding para, it is very strong.

Thomas Chelimsky, MD
Professor of Neurology
Tel 414-955-0619
tchelimsky@mcw.edu

Medical College of Wisconsin
8701 Watertown Plank Rd
Milwaukee, WI 53226

From: "Biaggioni, Italo" <italo.biaggioni@vumc.org>
Date: Sunday, October 13, 2019 at 6:51 PM
To: Wolfgang Singer <Singer.Wolfgang@mayo.edu>, 'Satish Raj' <satish.raj@ucalgary.ca>, Phillip Low <low@mayo.edu>, Mark Chapleau <mark-chapleau@uiowa.edu>, Thomas Chelimsky <tchelimsky@mcw.edu>, Gisela Chelimsky <gchelimsky@mcw.edu>, William Cheshire <cheshire@mayo.edu>, "rfreeman@bidmc.harvard.edu" <rfreeman@bidmc.harvard.edu>, "Benarroch, Eduardo E., M.D." <benarroch@mayo.edu>, Felicia Axelrod <Faxelrod@rcn.com>, David Goldstein <goldsteind@ninds.nih.gov>, Mike Joyner <joyner.michael@mayo.edu>, Horacio Kaufmann <Horacio.Kaufmann@nyumc.org>, Lucy Kaufmann <norcll01@nyumc.org>, David Robertson <david.robertson@vanderbilt.edu>, Rose Robertson <rosemarie.robertson@heart.org>, "Shibao, Cyndya" <cyndya.shibao@vumc.org>, Steve Vernino <Steven.Vernino@UTSouthwestern.edu>
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Subject: Re: AAS HPV Vaccine Statement

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I also agree. Iv suspender this will y be the last comment again our opinion and perhaps car can wait 2-3 weeks to compile all comments.

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From: Singer, Wolfgang, M.D. <Singer.Wolfgang@mayo.edu>
Sent: Sunday, October 13, 2019 3:31:22 PM
To: 'Satish Raj' <satish.raj@ucalgary.ca>; Low, Phillip A., M.D. <low@mayo.edu>; Biaggioni, Italo <italo.biaggioni@vumc.org>; Mark Chapleau <mark-chapleau@uiowa.edu>; Thomas Chelimsky <tchelimsky@mcw.edu>; Gisela Chelimsky <gchelimsky@mcw.edu>; Cheshire, William P., M.D. <cheshire@mayo.edu>; Roy Freeman <rfreeman@bidmc.harvard.edu>; Benarroch, Eduardo E., M.D. <benarroch@mayo.edu>; Felicia Axelrod <Faxelrod@rcn.com>; David Goldstein <goldsteind@ninds.nih.gov>; Joyner, Michael J., M.D. <joyner.michael@mayo.edu>; Horacio Kaufmann <Horacio.Kaufmann@nyumc.org>; Lucy Kaufmann <norcll01@nyumc.org>; David Robertson <david.robertson@vanderbilt.edu>; Rose Robertson <rosemarie.robertson@heart.org>; Shibao, Cyndya <cyndya.shibao@vumc.org>; Steven Vernino <Steven.Vernino@UTSouthwestern.edu>
Cc: Alex Barboi <ABarboi@northshore.org>; Amber Millen <amber@americanautonomicsociety.org>; Chris Gibbons <cgibbons@bidmc.harvard.edu>
Subject: RE: AAS HPV Vaccine Statement

I fully agree with the response. As a suggestion, the second to last paragraph ends with a clear, powerful statement. One could stop the response right there.

Wolfgang

From: Satish Raj [<mailto:satish.raj@ucalgary.ca>]

Sent: Sunday, October 13, 2019 4:28 PM

To: Low, Phillip A., M.D.; Italo Biaggioni; Mark Chapleau; Thomas Chelimsky; Gisela Chelimsky; Cheshire, William P., M.D.; Roy Freeman; Benarroch, Eduardo E., M.D.; Felicia Axelrod; David Goldstein; Joyner, Michael J., M.D.; Horacio Kaufmann; Lucy Kaufmann; David Robertson; Rose Robertson; Cyndya Shibao; Singer, Wolfgang, M.D.; Steven Vernino

Cc: Alex Barboi; Amber Millen; Chris Gibbons

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Colleagues,

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There has been a Letter to the Editor about our article that has been accepted by CAR. We have been asked to respond.

Please find attached the letter from Svetlana and the response that Alex, Chris and I have crafted.

Please look this over and confirm that you are willing to co-author the response. Please also email if there are significant changes to our response that you think are needed.

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If I do not hear from you, I will assume you are OK with this response (but would prefer to hear this from you).

Thank you,

Satish

From: Cheshire, William P., M.D.
Sent: Mon, 14 Oct 2019 15:26:46 +0000
To: 'Chapleau, Mark'; Satish Raj; Low, Phillip A., M.D.; Italo Biaggioni; Thomas Chelimsky; Gisela Chelimsky; Roy Freeman; Benarroch, Eduardo E., M.D.; Felicia Axelrod; Goldstein, David (NIH/NINDS) [E]; Joyner, Michael J., M.D.; Horacio Kaufmann; Lucy Kaufmann; David Robertson; Rose Robertson; Cyndya Shibao; Singer, Wolfgang, M.D.; Steven Vernino
Cc: Alex Barboi; Amber Millen; Chris Gibbons
Subject: RE: [External] AAS HPV Vaccine Statement

Excellent response. I am supportive and agree that the final paragraph could be omitted.

From: Chapleau, Mark [mailto:mark-chapleau@uiowa.edu]
Sent: Monday, October 14, 2019 11:18 AM
To: Satish Raj; Low, Phillip A., M.D.; Italo Biaggioni; Thomas Chelimsky; Gisela Chelimsky; Cheshire, William P., M.D.; Roy Freeman; Benarroch, Eduardo E., M.D.; Felicia Axelrod; David Goldstein; Joyner, Michael J., M.D.; Horacio Kaufmann; Lucy Kaufmann; David Robertson; Rose Robertson; Cyndya Shibao; Singer, Wolfgang, M.D.; Steven Vernino
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Mark

From: Satish Raj <satish.raj@ucalgary.ca>
Sent: Sunday, October 13, 2019 4:28 PM
To: Low, Phillip A., M.D. <low@mayo.edu>; Italo Biaggioni <italo.biaggioni@vumc.org>; Chapleau, Mark <mark-chapleau@uiowa.edu>; Thomas Chelimsky <tchelimsky@mcw.edu>; Gisela Chelimsky <gchelimsky@mcw.edu>; Cheshire, William P., M.D. <cheshire@mayo.edu>; Roy Freeman <rffreeman@bidmc.harvard.edu>; Benarroch, Eduardo E., M.D. <benarroch@mayo.edu>; Felicia Axelrod <Faxelrod@rcn.com>; David Goldstein <goldsteind@ninds.nih.gov>; Joyner, Michael J., M.D. <joyner.michael@mayo.edu>; Horacio Kaufmann <Horacio.Kaufmann@nyumc.org>; Lucy Kaufmann <norcll01@nyumc.org>; David Robertson <david.robertson@vanderbilt.edu>; Rose Robertson <rosemarie.robertson@heart.org>; Cyndya Shibao <cyndya.shibao@vumc.org>; Singer, Wolfgang, M.D. <Singer.Wolfgang@mayo.edu>; Steven Vernino <Steven.Vernino@UTSouthwestern.edu>
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From: Benarroch, Eduardo E., M.D.
Sent: Mon, 14 Oct 2019 14:25:32 +0000
To: Low, Phillip A., M.D.; 'Chelimsky, Thomas'; Biaggioni, Italo; Singer, Wolfgang, M.D.; 'Satish Raj'; Mark Chapleau; Chelimsky, Gisela; Cheshire, William P., M.D.; Roy Freeman; Felicia Axelrod; Goldstein, David (NIH/NINDS) [E]; Joyner, Michael J., M.D.; Horacio Kaufmann; Lucy Kaufmann; David Robertson; Rose Robertson; Shibao, Cyndya; Steven Vernino
Cc: Alex Barboi; Amber Millen; Chris Gibbons
Subject: RE: AAS HPV Vaccine Statement

I support the response

Thanks for the good work!

Eduardo

From: Benarroch, Eduardo E., M.D.
Sent: Monday, October 14, 2019 9:25 AM
To: Low, Phillip A., M.D.; 'Chelimsky, Thomas'; Biaggioni, Italo; Singer, Wolfgang, M.D.; 'Satish Raj'; Mark Chapleau; Chelimsky, Gisela; Cheshire, William P., M.D.; Roy Freeman; Felicia Axelrod; David Goldstein; Joyner, Michael J., M.D.; Horacio Kaufmann; Lucy Kaufmann; David Robertson; Rose Robertson; Shibao, Cyndya; Steven Vernino
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To: 'Chelimsky, Thomas'; Biaggioni, Italo; Singer, Wolfgang, M.D.; 'Satish Raj'; Mark Chapleau; Chelimsky, Gisela; Cheshire, William P., M.D.; Roy Freeman; Benarroch, Eduardo E., M.D.; Felicia Axelrod; David Goldstein; Joyner, Michael J., M.D.; Horacio Kaufmann; Lucy Kaufmann; David Robertson; Rose Robertson; Shibao, Cyndya; Steven Vernino
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Subject: RE: AAS HPV Vaccine Statement

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Thomas Chelimsky, MD
Professor of Neurology
Tel 414-955-0619
tchelimsky@mcw.edu
Medical College of Wisconsin
8701 Watertown Plank Rd
Milwaukee, WI 53226

From: "Biaggioni, Italo" <italo.biaggioni@vumc.org>

Date: Sunday, October 13, 2019 at 6:51 PM

To: Wolfgang Singer <Singer.Wolfgang@mayo.edu>, 'Satish Raj' <satish.raj@ucalgary.ca>, Phillip Low <low@mayo.edu>, Mark Chapleau <mark-chapleau@uiowa.edu>, Thomas Chelimsky <tchelimsky@mcw.edu>, Gisela Chelimsky <gchelimsky@mcw.edu>, William Cheshire <cheshire@mayo.edu>, "rfreeman@bidmc.harvard.edu" <rfreeman@bidmc.harvard.edu>, "Benarroch, Eduardo E., M.D." <benarroch@mayo.edu>, Felicia Axelrod <Faxelrod@rcn.com>, David Goldstein <goldsteind@ninds.nih.gov>, Mike Joyner <joyner.michael@mayo.edu>, Horacio Kaufmann <Horacio.Kaufmann@nyumc.org>, Lucy Kaufmann <norcll01@nyumc.org>, David Robertson <david.robertson@vanderbilt.edu>, Rose Robertson <rosemarie.robertson@heart.org>, "Shibao, Cyndya" <cyndya.shibao@vumc.org>, Steve Vernino <Steven.Vernino@UTSouthwestern.edu>
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I also agree. Iv suspender this will y be the last comment again our opinion and perhaps car can wait 2-3 weeks to compile all comments.

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Cc: Alex Barboi <ABarboi@northshore.org>; Amber Millen <amber@americanautonomicsociety.org>; Chris Gibbons <cgibbons@bidmc.harvard.edu>

Subject: RE: AAS HPV Vaccine Statement

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Cc: Alex Barboi; Amber Millen; Chris Gibbons

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Thank you,

Satish

From: Freeman, Roy L (HMFP - Neurology)
Sent: Mon, 14 Oct 2019 13:24:15 +0000
To: Satish Raj
Cc: low@mayo.edu; Italo 'Biaggioni; Mark Chapleau; Thomas Chelimsky; Gisela Chelimsky; William Cheshire; Eduardo E. M. D. Benarroch; Felicia Axelrod; Goldstein, David (NIH/NINDS) [E]; Michael Joyner; Horacio.Kaufmann@nyumc.org; Lucy Kaufmann; david.robertson@Vanderbilt.Edu; Rose Robertson; Cyndya Shibao; singer.wolfgang@mayo.edu; Steven A. Vernino; Alex Barboi; Amber Millen; Gibbons, Christopher (HMFP - Neurology)
Subject: Re: [External] AAS HPV Vaccine Statement

Excellent response
Roy

On Oct 13, 2019, at 5:27 PM, Satish Raj <satish.raj@ucalgary.ca> wrote:

Colleagues,

Our AAS HPV Vaccine Statement has been published online in CAR, and the Autonomic Neurosciences Publication is coming.

There has been a Letter to the Editor about our article that has been accepted by CAR. We have been asked to respond.

Please find attached the letter from Svetlana and the response that Alex, Chris and I have crafted.

Please look this over and confirm that you are willing to co-author the response. Please also email if there are significant changes to our response that you think are needed.

There is some time sensitivity to this. Please try to return this to us within 72 hours.

If I do not hear from you, I will assume you are OK with this response (but would prefer to hear this from you).

Thank you,

Satish

<HPV Statement Letter Response 2019Oct13.docx><AUTR-D-19-00148-2.pdf>

From: Goldstein, David (NIH/NINDS) [E]
Sent: Sun, 13 Oct 2019 22:12:37 -0400
To: Satish Raj
Subject: Re: AAS HPV Vaccine Statement

I agree with the content of this response.

Dave Goldstein

--

David S. Goldstein, MD PhD
Chief, Autonomic Medicine Section
CNP/DIR/NINDS/NIH
Email: goldsteind@ninds.nih.gov
iPhone: (b)(6)

To download Dr. Goldstein's e-book, Principles of Autonomic Medicine, go to
<https://neuroscience.nih.gov/ninds/Faculty/Profile/david-goldstein.aspx>
Then click Selected Publications.

From: Satish Raj <satish.raj@ucalgary.ca>
Date: Sunday, October 13, 2019 at 5:27 PM
To: "Low, Phillip A." <low@mayo.edu>, Italo Biaggioni <italo.biaggioni@vumc.org>, Mark Chapleau <mark-chapleau@uiowa.edu>, Thomas Chelimsky <tchelimsky@mcw.edu>, Gisela Chelimsky <gchelimsky@mcw.edu>, "Cheshire, William P., M.D." <cheshire@mayo.edu>, Roy Freeman <rfreeman@bidmc.harvard.edu>, "Benarroch, Eduardo E., M.D." <benarroch@mayo.edu>, Felicia Axelrod <Faxelrod@rcn.com>, David Goldstein <goldsteind@ninds.nih.gov>, "Joyner, Michael J., M.D." <joyner.michael@mayo.edu>, Horacio Kaufmann <Horacio.Kaufmann@nyumc.org>, Lucy Kaufmann <norcll01@nyumc.org>, "Robertson, David" <david.robertson@vanderbilt.edu>, Rose Robertson <rosemarie.robertson@heart.org>, Cyndya Shibao <cyndya.shibao@vumc.org>, "Singer, Wolfgang, M.D." <Singer.Wolfgang@mayo.edu>, Steven Vernino <Steven.Vernino@UTSouthwestern.edu>
Cc: Alex Barboi <ABarboi@northshore.org>, Amber Millen <amber@americanautonomicsociety.org>, Chris Gibbons <cgibbons@bidmc.harvard.edu>
Subject: AAS HPV Vaccine Statement

Colleagues,

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Thank you,

Satish

From: Satish Raj
Sent: Sun, 13 Oct 2019 21:27:46 +0000
To: Low, Phillip A., M.D.; Italo Biaggioni; Mark Chapleau; Thomas Chelimsky; Gisela Chelimsky; Cheshire, William P., M.D.; Roy Freeman; Benarroch, Eduardo E., M.D.; Felicia Axelrod; Goldstein, David (NIH/NINDS) [E]; Joyner, Michael J., M.D.; Horacio Kaufmann; Lucy Kaufmann; David Robertson; Rose Robertson; Cyndya Shibao; Singer, Wolfgang, M.D.; Steven Vernino
Cc: Alex Barboi; Amber Millen; Chris Gibbons
Subject: AAS HPV Vaccine Statement
Attachments: HPV Statement Letter Response 2019Oct13.docx, AUTR-D-19-00148-2.pdf

Colleagues,

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There has been a Letter to the Editor about our article that has been accepted by CAR. We have been asked to respond.

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If I do not hear from you, I will assume you are OK with this response (but would prefer to hear this from you).

Thank you,

Satish

Letter in Response About “Human papilloma vaccine (HPV) and Autonomic Disorders: A Position Statement from the American Autonomic Society”

Alexandru Barboi MD¹, Christopher H Gibbons MD², Felicia Axelrod MD³, Eduardo E Bennaroch MD PhD⁴, Italo Biaggioni MD⁵, Mark W Chapleau PhD⁶, Gisela Chelimsky MD⁷, Thomas Chelimsky MD⁸, William P. Cheshire MD⁹, Victoria E Claydon PhD¹⁰, Roy Freeman MD², David S Goldstein MD PhD¹¹, Michael J Joyner MD PhD¹², Horacio Kaufmann MD³, Phillip A Low MD⁴, Lucy Norcliffe-Kaufmann PhD¹³, David Robertson MD⁵, Cyndya A Shibao MD MSCI⁵, Wolfgang Singer MD⁴, Howard Snapper MD¹⁴, Steven Vernino MD PhD¹⁵, and Satish R Raj MD MSCI^{5,16}, on behalf of the American Autonomic Society

1 – Department of Neurology, NorthShore University Health System, Pritzker School of Medicine, University of Chicago, Chicago, IL, USA.

2 – Department of Neurology, Beth Israel Deaconess Medical Center, Harvard University, Boston, MA, USA

3 – Departments of Neurology, New York University, New York, NY, USA.

4 – Department of Neurology, Mayo Clinic, Rochester, MN, USA.

5 – Autonomic Dysfunction Center, Division of Clinical Pharmacology, Department of Medicine, Vanderbilt University School of Medicine, Nashville, TN, USA.

6 – Departments of Medicine & Molecular Physiology and Biophysics, University of Iowa, Iowa City, IA, USA.

7 – Department of Pediatrics, Medical College of Wisconsin, Milwaukee, WI, USA.

8 – Department of Neurology, Medical College of Wisconsin, Milwaukee, WI, USA.

9 – Department of Neurology, Mayo Clinic, Jacksonville, FL, USA.

10 – Department of Biomedical Physiology and Kinesiology, Simon Fraser University, Burnaby, BC, Canada.

11- Autonomic Medicine Section, National Institute of Neurological Diseases and Stroke, National Institutes of Health, Bethesda, MD, USA.

12 – Department of Anesthesia and Perioperative Medicine, Mayo Clinic, Rochester, MN, USA.

13 – Departments of Physiology & Neurosciences, New York University, New York, NY, USA.

14 - Cardiology Division, Wellstar Healthcare System, Atlanta, GA, USA

15 – Department of Neurology & Neurotherapeutics, UT Southwestern Medical Center, Dallas, TX, USA.

16 – Libin Cardiovascular Institute of Alberta, Department of Cardiac Sciences, University of Calgary, Calgary, AB, Canada.

Address for Correspondence:

Alexandru Barboi MD

American Autonomic Society

c/o Amber Millen, Executive Director

American Autonomic Society

9500 Gilman Drive, BSB 5006

La Jolla, CA 92093-0629

Dear Editor,

We would like to thank Dr. Blitshteyn for her comments on our statement on the human papillomavirus vaccine.^{1,2} Dr. Blitshteyn has highlighted that the case reports were not written to create an environment of fear, and not meant to cause a reduction in vaccination rates. It was not the intent of the statement to suggest that the case report authors were attempting to cause a panic; however, the reports by media of the complications associated with these small case reports have resulted in a biased public perception of vaccinations. This has resulted in an environment of fear, intentional or not, and caused a reduction in vaccination rates in many countries, and in some countries the vaccine has been withdrawn.^{1,3}

The Skufca study in Finland did provide valuable information on the incidence of POTS in a general population pre-vaccine.⁴ This was followed up by a larger, more recent study where 134,615 girls who received the HPV vaccine were followed through data in the Finnish Population Information System.⁵ These individuals were compared to the incidence of POTS in years prior to vaccination.⁵ The incidence of POTS in Finland actually *declined* following introduction of the HPV vaccine compared to the year prior.⁵ This very large data set provides powerful evidence of the non-association between the HPV vaccination and POTS.

As counterargument Dr. Blitshteyn offers several small case reports with very heterogenous descriptions that do not meet the medical definition of POTS, CRPS, or any other known medical condition. Although we agree that it is critical not to dismiss a safety signal, we would also strongly encourage future reports to 1) provide accurate descriptions of such conditions, 2) to avoid sweeping generalizations and 3) to provide a balanced review of the data without inflammatory statements that create a perception of bias. As noted in the Chandler paper, there were 'clusters' of signals noted in the VigiBase reports.⁶ These signals included some combination of headache, fatigue, dizziness and

syncope. A total of 66 individuals in the Chandler paper were noted to have 'POTS' in this cohort, which appears to reflect similar data from the European Medical Agency report (where over 80 cases of POTS were reported, but less than half actually met the diagnostic criteria for POTS in detailed case review).⁷

Case reports do play a valuable role in highlighting the potential risks associated with new vaccinations. Case reports are not designed, nor powered, to assess such risk. Only large epidemiologic studies are capable of clearly identifying whether a safety signal is noted in a population of individuals receiving vaccinations. We disagree with Dr. Blitshteyn that a large randomized placebo-controlled trial is the appropriate method to assess for risk using vaccinations. Such trials are appropriate to define whether such a treatment is effective compared to another treatment. However, such a study is not appropriate to define a small safety signal in a vaccine for several critical reasons:

- First, we don't believe it is ethical to ask someone to participate in an interventional trial primarily for the purpose of tracking adverse events.
- Second, such a study would require tens of thousands of individuals in both arms of the study to be powered appropriately to detect a rare event.
- Third, it would put tens of thousands of people at risk for cancer who receive placebo, and would put all their future associated sexual partners at risk.
- Finally, it would cause number of individuals to develop cancer, possibly fatal, in individuals who would not otherwise have developed cancer if they received a vaccine.

Taken in total, there is no scientifically or ethically valid reason for such a trial to be suggested to answer this question. The appropriate study design is a phase 4 post-marketing study of safety in the population, such as has been conducted in Finland, where the data has now definitively demonstrated there is no relationship between the HPV vaccination and POTS.⁵

All of the authors in this statement care for patients with POTS, and we encourage continued scientific discussion around this topic. We recommend that such future discourse provide a balanced, unbiased review of the data, with a focus on realistic suggestions that that could provide real answers to scientific questions.

REFERENCES:

1. Barboi A, Gibbons CH, Axelrod F, et al. Human papillomavirus (HPV) vaccine and autonomic disorders: a position statement from the American Autonomic Society. *Clinical autonomic research : official journal of the Clinical Autonomic Research Society* 2019.
2. Blitshteyn S. Human Papillomavirus (HPV) vaccines safety concerning POTS, CRPS and related conditions. *Clinical autonomic research : official journal of the Clinical Autonomic Research Society* 2020.
3. Butts BN, Fischer PR, Mack KJ. Human Papillomavirus Vaccine and Postural Orthostatic Tachycardia Syndrome: A Review of Current Literature. *J Child Neurol* 2017;32:956-965.
4. Skufca J, Ollgren J, Ruokokoski E, Lyytikainen O, Nohynek H. Incidence rates of Guillain Barre (GBS), chronic fatigue/systemic exertion intolerance disease (CFS/SEID) and postural orthostatic tachycardia syndrome (POTS) prior to introduction of human papilloma virus (HPV) vaccination among adolescent girls in Finland, 2002-2012. *Papillomavirus Res* 2017;3:91-96.
5. Skufca J, Ollgren J, Artama M, Ruokokoski E, Nohynek H, Palmu AA. The association of adverse events with bivalent human papilloma virus vaccination: A nationwide register-based cohort study in Finland. *Vaccine* 2018;36:5926-5933.
6. Chandler RE, Juhlin K, Fransson J, Caster O, Edwards IR, Noren GN. Current Safety Concerns with Human Papillomavirus Vaccine: A Cluster Analysis of Reports in VigiBase((R)). *Drug Saf* 2017;40:81-90.
7. Agency EM. Assessment report: Review under Article 20 of Regulation (EC) No 726/2004. Human papillomavirus (HPV) vaccines. 2015.

Clinical Autonomic Research

Human Papillomavirus (HPV) vaccines safety concerning POTS, CRPS and related conditions. --Manuscript Draft--

Manuscript Number:	AUTR-D-19-00148
Full Title:	Human Papillomavirus (HPV) vaccines safety concerning POTS, CRPS and related conditions.
Article Type:	Letter to the Editor
Keywords:	HPV vaccines, postural orthostatic tachycardia syndrome, complex regional pain syndrome
Corresponding Author:	Svetlana Blitshteyn, MD University at Buffalo - The State University of New York Williamsville, NY UNITED STATES
Corresponding Author Secondary Information:	
Corresponding Author's Institution:	University at Buffalo - The State University of New York
Corresponding Author's Secondary Institution:	
First Author:	Svetlana Blitshteyn, MD
First Author Secondary Information:	
Order of Authors:	Svetlana Blitshteyn, MD
Order of Authors Secondary Information:	
Funding Information:	
Abstract:	

Title: Human Papillomavirus (HPV) vaccines safety concerning POTS, CRPS and related conditions.

Author: Svetlana Blitshteyn¹, MD

¹Department of Neurology, University at Buffalo Jacobs School of Medicine and Biomedical Sciences, Buffalo, New York, USA

Corresponding Author and Address:

Svetlana Blitshteyn, MD

300 International Drive, Suite 100, Williamsville, NY 14221

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E-mail: sb25@buffalo.edu

Word Count: 836

Funding: none

Conflicts of Interest: Svetlana Blitshteyn has served as a medical expert witness on cases of POTS and other neurologic disorders after Gardasil vaccine.

Key Words: HPV vaccines, postural orthostatic tachycardia syndrome, complex regional pain syndrome

“Without the possibility of open debate, science simply ceases to exist.”

-Jan Vandenbroucke, MD

Dear Editor,

I appreciate the American Autonomic Society’s position statement on HPV vaccines and autonomic disorders and agree with its conclusion that given the existing evidence to date, a causal relationship has not been supported (1). However, I disagree with the assertion that my case series and those of others from Denmark, Japan, Mexico, Italy and other countries “created fear resulting in decreased vaccination rates.” (1) Case series like these are not written by the authors with the intent of gaining media attention or creating fear. Rather, they are written with the intent of alerting the scientific community about a possible safety signal.

Although the European Medical Agencies concluded in 2015 that there is no link between HPV vaccines and POTS, their conclusion was not based on randomized clinical studies set out to determine the incidence of POTS in HPV vaccinated vs. unvaccinated individuals. While such a study remains to be done, we cannot dismiss the mounting evidence from different countries of patients developing POTS, CRPS and other related conditions after HPV vaccines, given the appropriate temporal association with vaccination and plausible biological mechanism as outlined in the recent review. (2)

In the argument for HPV vaccines safety with respect to POTS, CRPS and related conditions, the position statement relies on three references. The first is a report from the Global Advisory Committee on Vaccine Safety meeting, where, while acknowledging that cases of POTS and CRPS continue to be reported especially from Denmark and Japan, no causal relationship between HPV vaccines and POTS and CRPS was identified. (3) It’s unclear from examining the

methodology of that reference how the committee arrived at that conclusion when there has not been a study done to address that question.

The second reference is the study by Arana et al that found a total of 29 patients with POTS worldwide in the VAERS database between 2006 and 2015. (4) VAERS is a voluntary reporting system, with only 1-10% population filing reports, according to the National Vaccine Information Center. (5) A very low number of confirmed POTS cases found in the VAERS database in the span of 9 years worldwide is obviously an underestimation, considering that the author of this Letter has been personally involved in the cases of at least as many patients with post-HPV vaccination POTS over the years. Failure to capture POTS cases in VAERS database, coupled with under-diagnosis of POTS by medical professionals and a lack of diagnostic codes for POTS in the US, would yield very few cases of POTS in VAERS database as evidenced by Arana's study, making any conclusions of the true incidence rate of post-HPV vaccination POTS based on VAERS database unreliable.

The third reference is a study from Finland that was designed to establish the incidence rate of POTS in Finland prior to HPV vaccination as a reference point for future HPV vaccine safety evaluations. (6) The study itself never ascertained the incidence rate of POTS in the vaccinated vs. the unvaccinated population so this study is not particularly relevant to the argument for HPV vaccine safety record with respect to POTS.

In summary, none of the 3 studies that the position statement referenced has thoroughly and systematically investigated via prospective randomized controlled studies whether there is a higher incidence of POTS, CRPS and related conditions in HPV vaccinated vs. unvaccinated individuals, which makes the argument for HPV vaccine safety with respect to POTS, CRPS and related conditions largely unsubstantiated.

Unfortunately, not referenced in the position statement is a study of HPV vaccines adverse events by Chandler et al. In that study, which utilized Vigibase, the WHO international database of suspected adverse drug reactions, a combination of headache and dizziness with either fatigue or syncope was found to be more commonly reported in HPV vaccine reports compared with non-HPV vaccine reports for females aged 9–25 years. (7) This disproportionality remained when results were stratified by age and when those countries reporting the signals of CRPS (Japan) and POTS (Denmark) were excluded. Cluster analysis in that study also revealed additional reports of serious adverse events, including hospitalization, following HPV vaccination that overlapped in signs and symptoms with safety signals for POTS, CRPS, and CFS. (7)

Much like Guillain-Barré syndrome or acute disseminated encephalomyelitis, POTS, CRPS and other related conditions may occur in certain healthy individuals, possibly with a genetic predisposition toward adverse events, following immunization with HPV vaccines. In the future, identifying those at-risk individuals through genetic testing might be possible as part of personalized medicine, which may lead to a reduction of serious adverse events following vaccination. Until those tests become available, detailed package insert and informed consent serve to acknowledge the possible rare adverse events following vaccination. Including POTS, CRPS and related conditions as part of the informed consent for HPV vaccines rather than denying their occurrence after immunization is a better way to ensure vaccination compliance and improved HPV vaccination rates in the United States.

References

1. Barboi A, Gibbons CH, Axelrod F et al. “Human papillomavirus (HPV) vaccine and autonomic disorders: a position statement from the American Autonomic Society.” Clin Auton Res. 2019 Sep 2. doi: 10.1007/s10286-019-00608-w
2. Blitshteyn S, Brinth L, Hendrickson JE, Martinez-Lavin M. Autonomic dysfunction and HPV immunization: an overview. Immunol Res. 2018; 66: 744-754.
3. GAVS Meeting of the Global Advisory Committee on Vaccine Safety, 7–8 June 2017. Wkly Epidemiol Rec 2017; 92: 393–402.
4. Arana J, Mba-Jonas A, Jankosky C et al. Reports of postural orthostatic tachycardia syndrome after human papillomavirus vaccination in the vaccine adverse event reporting system. J Adolesc Health 2017; 61: 577–582.
5. National Vaccine Information Center (NVIC). An Analysis by the National Vaccine Information Center of Gardasil & Menactra Adverse Event Reports to the Vaccine Adverse Events Reporting System (VAERS), February 2009.
<http://www.nvic.org/Downloads/NVICGardasilvsMenactraVAERSReportFeb-2009u.aspx>
6. Skufca J, Ollgren J, Ruokokoski E, Lyytikäinen O, Nohynek H. Incidence rates of Guillain Barré (GBS), chronic fatigue/systemic exertion intolerance disease (CFS/SEID) and postural orthostatic tachycardia syndrome (POTS) prior to introduction of human papilloma virus (HPV) vaccination among adolescent girls in Finland, 2002–2012. Papillomavirus Res 2017; 3: 91–96.

7. Chanlder RE, Juhlin K, Fransson J et al. "Current Safety Concerns with Human Papillomavirus Vaccine: A Cluster Analysis of Reports in VigiBase®." *Drug Saf* 2017; 40: 81–90.

From: Amber Millen
Sent: Thu, 19 Sep 2019 13:07:00 -0700
To: Satish Raj; Chelimsky, Gisela; Steven Vernino; Cheshire, William P.; Singer, Wolfgang; Shibao, Cyndya; Snapper, Howard; Victoria Claydon; Goldstein, David (NIH/NINDS) [E]; Lucy Norcliffe-Kaufmann
Subject: AAS minutes from 18SEP2019
Attachments: AAS BoD Meeting Minutes 2019Sep18.pdf

Hi all,

Here are the minutes from yesterday's Board call.

Cheers,
Amber

Amber Millen | Executive Director, American Autonomic Society
9500 Gilman Drive | BSB 5006, MC 0629 | La Jolla, CA 92093-0629 | USA
E: amber@americanautonomicsociety.org | T: (858) 534-3865 | F: (858) 534-1445
www.americanautonomicsociety.org | Follow us: @AASAutonomic



American Autonomic Society Board of Directors – Meeting Agenda
Wednesday, September 18, 2019 (5pm EDT; 2pm PDT)

(b)(4)



American Autonomic Society Board of Directors – Meeting Agenda

Wednesday, September 18, 2019 (5pm EDT; 2pm PDT)

(b)(4)



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(b)(4)



American Autonomic Society Board of Directors – Meeting Agenda

Wednesday, September 18, 2019 (5pm EDT; 2pm PDT)

(b)(4)



From: amber@americanautonomicsociety.org
Sent: Tue, 17 Sep 2019 12:44:00 -0700
To: Cheshire, William P.; Satish Raj; Norcliffe-Kaufmann, Lucy; Shibao, Cyndya; Chelimsky, Gisela; Singer, Wolfgang; Goldstein, David (NIH/NINDS) [E]; Steven Vernino <Steven.; Howard Snapper; Victoria Claydon; Sabharwal, Rasna; Vera-Ellen Lucci
Subject: Update: AAS BOARD MONTHLY CONFERENCE CALL
Attachments: AAS BoD Meeting Agenda 2019Sep18.docx, Consensus stmt on sodium.pdf, Wenning email.pdf

Attached is a draft agenda for tomorrow's board call. Please forward any additional agenda items by Wednesday morning. -Amber

AAS BOARD MONTHLY CONFERENCE CALL

3rd Wednesday of the month (2 pm Pacific / 3 pm Mountain / 4 pm Central / 5 pm Eastern)

US: (b)(6)

Canada: (b)(6)

Meeting ID: (b)(6)

International numbers available: (b)(6)

Amber Millen | Executive Director, American Autonomic Society
9500 Gilman Drive | BSB 5006, MC 0629 | La Jolla, CA 92093-0629 | USA
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American Autonomic Society Board of Directors – Meeting Agenda
Wednesday, September 18, 2019 (5pm EDT; 2pm PDT)

(b)(4)



American Autonomic Society Board of Directors – Meeting Agenda
Wednesday, September 18, 2019 (5pm EDT; 2pm PDT)

(b)(4)



Subject: The Clearwater Consensus on Salt Supplementation

Date: Tuesday, August 27, 2019 at 6:52:28 AM Pacific Daylight Time

From: Cheshire, William P., M.D.

To: Satish Raj (satish.raj@ucalgary.ca), Steven Vernino, 'Norcliffe-Kaufmann, Lucy', Singer, Wolfgang, M.D., Goldstein, David (NIH/NINDS) [E], Gisela Chelimsky (gchelimsky@mcw.edu), Shibao, Cyndya (cyndya.shibao@Vanderbilt.Edu), Snapper, Howard (Howard.Snapper@wellstar.org), Victoria Claydon

CC: 'Amber Millen' (amber@americanautonomicsociety.org)

Dear AAS Board,

As we have been formalizing our process for approving internal and external position statements, I have a proposal for which I request consideration by the Board in planning for our November 2019 meeting.

I would like to initiate and lead a panel to develop a consensus statement on salt. The dilemma in clinical practice is that added salt, while clearly beneficial in treating syncope, orthostatic intolerance, and orthostatic hypotension, is also the single most modifiable risk factor for developing hypertension and its sequelae. Currently we lack sufficient evidence or even consensus-based guidance on how long to continue salt supplementation in autonomic patients. For some it may be a matter of balancing one risk against another.

Some of my long-term POTS patients, for example, are now middle-aged and have developed hypertension; should they continue taking extra salt, and if so, how much? When is it appropriate to cut back on salt? Other questions are how to titrate salt when OH and HTN coexist, how long to continue it, and how to balance salt with other interventions. How should patients be monitored long-term; should monitoring of BP be standardized in terms of posture, time of day, clinic vs. ambulatory devices, or home devices? What should the BP target be in these patients? What other parameters (creatinine, etc.) should be followed if salt supplementation is continued in patients with HTN?

The impetus for this set of questions comes from an article I wrote for Autonomic Neuroscience in 2014 (attached).

I think Clearwater is a good place to hold the initial meeting. We can publish our results as "The Clearwater Consensus," which sounds nice because salt and water go together. To meet in, for example, Salt Lake City or at the Dead Sea (in Hebrew, it is the Salt Sea) would be too salty for my taste. The name also suggests clarity.

So my request is to reserve a room to meet for 60-90 minutes during the AAS meeting. This would function much like Roy Freeman's consensus group on OH that met a decade ago (it was a daunting task, but worth it). We will identify the important questions (some answerable, others not) and divide them up among the group to report back on, and together by subsequent e-mail or conference calls assemble a statement that would eventually be submitted to the AAS Board for approval prior to potential publication in CAR and AN.

Potential members of this workgroup would be (and I welcome your suggestions – please add your name if you are interested): Raj, Freeman, Gibbons, Jordan, Wieling, Cortelli, Goldstein, Jacob, Levine, Sandroni, Singer, Hilz, Schondorf, Stewart, Biaggioni, Shibao. I would also invite Bill Haley, who is not an AAS member, but is an international expert on HTN [b)(6)] from Mayo Florida).

Bill

William P. Cheshire, Jr., M.D.
Professor of Neurology, Mayo Clinic

Phone: 904-953-2000
Secretary: 904-953-7228
Fax: 904-953-0757
E-mail: cheshire@mayo.edu

Mayo Clinic

4500 San Pablo Rd.
Jacksonville, FL 32224
www.mayoclinic.org

Subject: Fwd: AAS

Date: Monday, September 2, 2019 at 1:55:36 AM Pacific Daylight Time

From: Gregor Wenning

To: amber@americanautonomicsociety.org

Prof. Gregor K Wenning MD PhD MSc FAAS FEAN

Chair Division of Neurobiology INBU

Director Dysautonomia Center DACI

Medical University

Anichstraße 35

6020 Innsbruck

Austria

gregor.wenning@i-med.ac.at

T +43 676 596 4772

Anfang der weitergeleiteten Nachricht:

Von: Gregor Wenning (b)(6)@icloud.com>

Datum: 2. September 2019 um 09:54:25 WESZ

An: autonomic.research@ucalgary.ca

Kopie: Horacio.Kaufmann@nyumc.org, cgibbons@bidmc.harvard.edu, cheshire@mayo.edu,
Singer.Wolfgang@mayo.edu

Betreff: AAS

Dear Satish

As you know there are a number of European autonomic Units including Bonn, Bologna, Erlangen, London, Toulouse and Innsbruck's Center for Dysautonomia which will be formally opened this October

(DACI)

In my view the these groups might be represented more consistently in your annual AAS Meetings
Financial issues no longer count too much since there are more than 10 companies working on MSA therapies

Please consider this issue in your next BoD meeting this coming November

Best regards

Gregor

Prof. Gregor K Wenning MD PhD MSc FEAN

Chair Division of Neurobiology INBU

Director Dysautonomia Center DACI

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6020 Innsbruck

Austria

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T +43 676 596 4772

From: Amber Millen
Sent: Wed, 18 Sep 2019 12:48:53 -0700
To: Satish Raj; Steven Vernino; Cheshire, William P.; Singer, Wolfgang; Chelimsky, Gisela; Shibao, Cyndya; Snapper, Howard; Victoria Claydon; Goldstein, David (NIH/NINDS) [E]; Lucy Norcliffe-Kaufmann
Subject: Updated agenda for today's call
Attachments: AAS BoD Meeting Agenda 2019Sep18.docx

Here is an updated agenda for the call today. Talk to everyone in a little over an hour! -Amber

American Autonomic Society Board of Directors – Meeting Agenda
Wednesday, September 18, 2019 (5pm EDT; 2pm PDT)

(b)(4)

American Autonomic Society Board of Directors – Meeting Agenda

Wednesday, September 18, 2019 (5pm EDT; 2pm PDT)

(b)(4)



From: Amber Millen
Sent: Thu, 15 Aug 2019 13:35:35 -0700
To: Satish Raj; Steven Vernino; Cheshire, William P.; Singer, Wolfgang; Goldstein, David (NIH/NINDS) [E]; Chelimsky, Gisela; Lucy Norcliffe-Kaufmann; Shibao, Cyndya; Snapper, Howard; Victoria Claydon
Subject: AAS Board Call 2019Aug14 Minutes
Attachments: AAS BoD Meeting Minutes 2019Aug14.pdf

The minutes from yesterday's AAS Board call are attached.

Amber Millen | Executive Director, American Autonomic Society
9500 Gilman Drive | BSB 5006, MC 0629 | La Jolla, CA 92093-0629 | USA
E: amber@americanautonomicsociety.org | T: (858) 534-3865 | F: (858) 534-1445
www.americanautonomicsociety.org | Follow us: @AASAutonomic



American Autonomic Society Board of Directors – Meeting Minutes
Wednesday, August 14, 2019 (5pm EDT; 2pm PDT)

(b)(4)



American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, August 14, 2019 (5pm EDT; 2pm PDT)

(b)(4)



American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, August 14, 2019 (5pm EDT; 2pm PDT)

(b)(4)



American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, August 14, 2019 (5pm EDT; 2pm PDT)

(b)(4)



From: Amber Millen
Sent: Wed, 17 Jul 2019 16:01:19 -0700
To: Satish Raj; Lucy Norcliffe-Kaufmann; Cheshire, William P.; Steven Vernino
<Steven.; Singer, Wolfgang; Goldstein, David (NIH/NINDS) [E]; Shibao, Cyndya; Chelimsky, Gisela;
Snapper, Howard; Victoria Claydon
Cc: Sabharwal, Rasna; Vera-Ellen Lucci
Subject: AAS Board Meeting Minutes 2019Jul17
Attachments: AAS BoD Meeting Minutes 2019Jul17.pdf

American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, July 17, 2019 (5pm EDT; 2pm PDT)

(b)(4)

American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, July 17, 2019 (5pm EDT; 2pm PDT)

(b)(4)



American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, July 17, 2019 (5pm EDT; 2pm PDT)

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American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, July 17, 2019 (5pm EDT; 2pm PDT)

(b)(4)



American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, July 17, 2019 (5pm EDT; 2pm PDT)

(b)(4)



From: Amber Millen
Sent: Thu, 13 Jun 2019 13:51:31 -0700
To: Satish Raj; Singer, Wolfgang; Steven Vernino <Steven.; Cheshire, William P.; Chelimsky, Gisela; Snapper, Howard; Victoria Claydon; Norcliffe-Kaufmann, Lucy; Goldstein, David (NIH/NINDS) [E]; Vera-Ellen Lucci; Sabharwal, Rasna; Shibao, Cyndya A (University)
Subject: AAS Minutes 061219
Attachments: AAS BoD Meeting Minutes 2019Jun12.pdf

Hi all,

Attached are the minutes from yesterday's AAS Board call.

The next call is scheduled for Wednesday, July 17.

Please respond by return email (no need to reply all) to let me know if you will be able to participate. We almost did not have a quorum yesterday so need to be sure to avoid the same situation for future calls.

Cheers,
Amber

Amber Millen | Executive Director, American Autonomic Society
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American Autonomic Society Board of Directors – Meeting Minutes
Wednesday, June 12, 2019 (5pm EDT; 2pm PDT)

(b)(4)

American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, June 12, 2019 (5pm EDT; 2pm PDT)

(b)(4)



American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, June 12, 2019 (5pm EDT; 2pm PDT)

(b)(4)



From: Chelimsky, Gisela
Sent: Wed, 12 Jun 2019 21:03:28 +0000
To: Amber Millen; Satish Raj; Singer, Wolfgang; Steven Vernino <Steven.; Cheshire, William P.; Shibao, Cyndya; Snapper, Howard; Victoria Claydon; Norcliffe-Kaufmann, Lucy; Goldstein, David (NIH/NINDS) [E]
Subject: RE: HPV Info postcards revised - for Board call

The HPV vaccine is now recommended to age like 40

From: Amber Millen <amber@americanautonomicsociety.org>
Sent: Wednesday, June 12, 2019 3:48 PM
To: Satish Raj <satish.raj@ucalgary.ca>; Singer, Wolfgang <Singer.Wolfgang@mayo.edu>; Steven Vernino <Steven. <Steven.Vernino@utsouthwestern.edu>; Cheshire, William P. <cheshire@mayo.edu>; Chelimsky, Gisela <gchelimsky@mcw.edu>; Shibao, Cyndya <cyndya.shibao@vanderbilt.edu>; Snapper, Howard <Howard.Snapper@wellstar.org>; Victoria Claydon <victoria_claydon@sfu.ca>; Norcliffe-Kaufmann, Lucy <Lucy.Norcliffe-Kaufmann@nyumc.org>; Goldstein, David (NIH/NINDS) <goldsteind@ninds.nih.gov>
Subject: FW: HPV Info postcards revised - for Board call

ATTENTION: This email originated from a sender outside of MCW. Use caution when clicking on links or opening attachments.

Sorry, just saw this while checking emails in preparation for the call in 15 minutes.

So many abstracts to process...

From: Satish Raj <satish.raj@ucalgary.ca>
Date: Tuesday, June 11, 2019 at 7:09 PM
To: Amber Millen <amber@americanautonomicsociety.org>
Cc: "Victoria Claydon - Simon Fraser University (victoria_claydon@sfu.ca)" <victoria_claydon@sfu.ca>
Subject: FW: HPV Info postcards revised

Amber,

Could you please send this to the Board to discuss at tomorrow's meeting in the POTS HPV portion of the discussion?

Thanks,

Satish

From: Battersby, Lupin <lupin.battersby@fraserhealth.ca>
Sent: June 11, 2019 9:27 AM
To: Satish Raj <satish.raj@ucalgary.ca>; Victoria Claydon <victoria_claydon@sfu.ca>; 'Runte, Mary' <mary.runte@uleth.ca>; 'Vera-Ellen Lucci' <vlucci@sfu.ca>
Subject: RE: HPV Info postcards revised

Hi Vic and Satish,

I've incorporated your suggested edits Vic and I softened the title although not as soft as you suggested Satish as it is a bit wordy for a title in my opinion but of course happy to change it if all agree.

Best,
Lupin

From: Satish Raj [<mailto:satish.raj@ucalgary.ca>]

Sent: Monday, June 10, 2019 8:49 PM

To: Victoria Claydon <victoria_claydon@sfu.ca>; Battersby, Lupin <lupin.battersby@fraserhealth.ca>; 'Runte, Mary' <mary.runte@uleth.ca>; 'Vera-Ellen Lucci' <vlucci@sfu.ca>

Subject: Re: HPV Info postcards revised

Vic & Lupin,

I think that this is better.

The only thing I wonder about is whether we should "soften" it a bit by saying "No proven link" instead of "NOT linked". The former is more in keeping with the statement.

Cheers,

Satish

From: Victoria Claydon <victoria_claydon@sfu.ca>

Date: Monday, June 10, 2019 at 5:05 PM

To: "'Battersby, Lupin'" <lupin.battersby@fraserhealth.ca>, Satish Raj <satish.raj@ucalgary.ca>, Mary Runte <mary.runte@uleth.ca>, 'Vera-Ellen Lucci' <vlucci@sfu.ca>, "'Battersby, Lupin'" <lupin.battersby@fraserhealth.ca>

Subject: RE: HPV Info postcards revised

Dear All,

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Best wishes, Vic

From: Cheshire, William P., M.D.
Sent: Wed, 12 Jun 2019 21:01:52 +0000
To: 'Steven Vernino'; Amber Millen
Cc: Satish Raj; Singer, Wolfgang, M.D.; Chelimsky, Gisela; Shibao, Cyndya; Snapper, Howard; Victoria Claydon; Norcliffe-Kaufmann, Lucy; Goldstein, David (NIH/NINDS) [E]
Subject: RE: HPV Info postcards revised - for Board call

I am on call and will participate as I am able.

From: Steven Vernino [mailto:Steven.Vernino@UTSouthwestern.edu]
Sent: Wednesday, June 12, 2019 4:58 PM
To: Amber Millen
Cc: Satish Raj; Singer, Wolfgang, M.D.; Cheshire, William P., M.D.; Chelimsky, Gisela; Shibao, Cyndya; Snapper, Howard; Victoria Claydon; Norcliffe-Kaufmann, Lucy; Goldstein, David (NIH/NINDS)
Subject: [EXTERNAL] Re: HPV Info postcards revised - for Board call

I'll be a few minutes late to get on the call

Sent from my iPhone

On Jun 12, 2019, at 3:47 PM, Amber Millen <amber@americanautonomicsociety.org> wrote:

Sorry, just saw this while checking emails in preparation for the call in 15 minutes.

So many abstracts to process...

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Best wishes, Vic
<HPV Info.V5.pdf>

The future of medicine, today.

From: Singer, Wolfgang, M.D.
Sent: Wed, 12 Jun 2019 20:50:26 +0000
To: 'Amber Millen'; Satish Raj; Steven Vernino <Steven.; Cheshire, William P., M.D.; Chelimsky, Gisela; Shibao, Cyndya; Snapper, Howard; Victoria Claydon; Norcliffe-Kaufmann, Lucy; Goldstein, David (NIH/NINDS) [E]
Subject: RE: HPV Info postcards revised - for Board call

I like it!

Just a reminder that I am in clinic and had to decline the invitation to the call.

Wolfgang

From: Amber Millen [mailto:amber@americanautonomicsociety.org]
Sent: Wednesday, June 12, 2019 3:48 PM
To: Satish Raj; Singer, Wolfgang, M.D.; Steven Vernino <Steven.; Cheshire, William P., M.D.; Chelimsky, Gisela; Shibao, Cyndya; Snapper, Howard; Victoria Claydon; Norcliffe-Kaufmann, Lucy; Goldstein, David (NIH/NINDS)
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Best wishes, Vic

HPV vaccination: No link to POTS or dysautonomia

Obtained by ICANdecide.org via FOIA



AAS endorsed a careful review of the research evidence and concluded there is **no** scientific evidence that HPV* vaccination causes POTS/dysautonomia.



POTS or dysautonomia, conditions affecting blood pressure and heart rate, are often found in teenagers and youth. Some people wondered if there was a connection to the HPV vaccination. No link has been found.



For more information see the AAS position statement: americanautonomicsociety.org



**FOR ALL
YOUTH**

The HPV vaccine is for boys **and** girls aged 11-12 years.

7

**CANCERS
PREVENTED**

HPV vaccination can help prevent 7 cancers.



SAFE

270M people vaccinated with **no** patterns of adverse events found.

*Human papilloma virus

From: amber@americanautonomicsociety.org
Sent: Mon, 10 Jun 2019 17:21:00 -0700
To: Cheshire, William P.; Satish Raj; Norcliffe-Kaufmann, Lucy; Shibao, Cyndya; Chelimsky, Gisela; Singer, Wolfgang; Goldstein, David (NIH/NINDS) [E]; Steven Vernino <Steven.; Howard Snapper; Victoria Claydon; Sabharwal, Rasna; Vera-Ellen Lucci
Subject: Update: AAS BOARD MONTHLY CONFERENCE CALL
Attachments: AAS BoD Meeting Agenda 2019Jun12.docx

REMINDER: AAS BOARD MONTHLY CONFERENCE CALL

AGENDA ATTACHED

~~3rd Wednesday of the month~~ (2 pm Pacific / 3 pm Mountain / 4 pm Central / 5 pm Eastern)

US: (b)(6)

Canada: (b)(6)

Meeting ID: (b)(6)

International numbers available: (b)(6)

Amber Millen, Executive Director
American Autonomic Society
9500 Gilman Drive, BSB 5006, MC 0629
La Jolla, CA 92093-0629 USA
Office (858) 534-3865, Fax (858) 534-1445
Email: amber@americanautonomicsociety.org
Website: <http://americanautonomicsociety.org/>

American Autonomic Society Board of Directors – Meeting Agenda
Wednesday, June 12, 2019 (5pm EDT; 2pm PDT)

(b)(4)



From: Victoria Claydon
Sent: Wed, 22 May 2019 10:04:02 -0700
To: 'Singer, Wolfgang, M.D.'; 'Satish Raj'; 'Cheshire, William P., M.D.'
Cc: 'Amber Millen'; 'Steven Vernino <Steven.>'; 'Chelimsky, Gisela'; 'Norcliffe-Kaufmann, Lucy'; 'Shibao, Cyndya'; Goldstein, David (NIH/NINDS) [E]; 'Snapper, Howard'; 'Sabharwal, Rasna'; 'Vera-Ellen Lucci'
Subject: RE: [EXTERNAL] RE: RE: AAS Board Meeting Minutes 04/17/19

Hi Wolfgang,

Thanks for these suggestions – we can certainly incorporate them if they will address the concerns raised. It would be helpful to know if others who shared your concerns feel this would be the best way to go, and then we can get back to the KT team and incorporate the edits.

Best wishes, Vic

From: Singer, Wolfgang, M.D. [mailto:Singer.Wolfgang@mayo.edu]
Sent: May 22, 2019 10:01 AM
To: 'Satish Raj' <satish.raj@ucalgary.ca>; Cheshire, William P., M.D. <cheshire@mayo.edu>; Victoria Claydon <victoria_claydon@sfu.ca>
Cc: Amber Millen <amber@americanautonomicsociety.org>; Steven Vernino <Steven.Vernino@utsouthwestern.edu>; Chelimsky, Gisela <gchelimsky@mcw.edu>; Norcliffe-Kaufmann, Lucy <Lucy.Norcliffe-Kaufmann@nyumc.org>; Shibao, Cyndya <cyndya.shibao@vanderbilt.edu>; Goldstein, David (NIH/NINDS) <goldsteind@ninds.nih.gov>; Snapper, Howard <Howard.Snapper@wellstar.org>; Sabharwal, Rasna <rasna-sabharwal@uiowa.edu>; Vera-Ellen Lucci <vlucci@sfu.ca>
Subject: RE: [EXTERNAL] RE: RE: AAS Board Meeting Minutes 04/17/19

If we want to stick with the infographic, my suggestions would be as follows:

- 1) Change the title to “HPV vaccination is not linked to Dysautonomia”
- 2) I think it is fine to reference prevented cancers, the CDC recommendation, and the number of people having received the vaccine without a clear AE pattern identified, but would keep that in smaller font and more as a background section
- 3) Maybe add a sentence that because POTS tends to occur in teenagers and young adults, the question has been raised if there could be a connection between POST and HPV vaccine
- 4) In larger font and even more highlighted would relay the main society-endorsed statement that the AAS endorses a careful review of the evidence that concluded that there is no scientific evidence that that HPV vaccination causes POTS/dysautonomia

Wolfgang

From: Satish Raj [mailto:satish.raj@ucalgary.ca]
Sent: Wednesday, May 22, 2019 11:44 AM
To: Cheshire, William P., M.D.; Singer, Wolfgang, M.D.; Victoria Claydon
Cc: Amber Millen; Steven Vernino <Steven.>; Chelimsky, Gisela; Norcliffe-Kaufmann, Lucy; Shibao, Cyndya; Goldstein, David (NIH/NINDS); Snapper, Howard; Sabharwal, Rasna; Vera-Ellen Lucci
Subject: [EXTERNAL] RE: RE: AAS Board Meeting Minutes 04/17/19

Bill,

I think that additional ways of Knowledge Dissemination such as YouTube would be great.

What we need acutely are thoughts from those that feel that this infographic is too promotional of the vaccine on ways to re-message it to deliver the ideal message.

Thoughts?

Satish

From: Cheshire, William P., M.D. <cheshire@mayo.edu>

Sent: May 22, 2019 9:07 AM

To: Singer, Wolfgang, M.D. <Singer.Wolfgang@mayo.edu>; Victoria Claydon <victoria_claydon@sfu.ca>

Cc: Amber Millen <amber@americanautonomicsociety.org>; Satish Raj <satish.raj@ucalgary.ca>; Steven Vernino <Steven.Vernino@utsouthwestern.edu>; Chelimsky, Gisela <gchelimsky@mcw.edu>; Norcliffe-Kaufmann, Lucy <Lucy.Norcliffe-Kaufmann@nyumc.org>; Shibao, Cyndya <cyndya.shibao@vanderbilt.edu>; Goldstein, David (NIH/NINDS) <goldsteind@ninds.nih.gov>; Snapper, Howard <Howard.Snapper@wellstar.org>; Sabharwal, Rasna <rasna-sabharwal@uiowa.edu>; Vera-Ellen Lucci <vlucci@sfu.ca>

Subject: RE: [EXTERNAL] RE: AAS Board Meeting Minutes 04/17/19

I agree with Wolfgang and think that the infographic oversimplifies the issue and appears too promotional.

Another strategy could be to produce an educational YouTube video with 1-3 AAS members having a conversation about this topic and addressing FAQs.

From: Singer, Wolfgang, M.D.

Sent: Friday, May 17, 2019 11:40 PM

To: Victoria Claydon

Cc: Amber Millen; Satish Raj; Cheshire, William P., M.D.; Steven Vernino <Steven.; Chelimsky, Gisela; Norcliffe-Kaufmann, Lucy; Shibao, Cyndya; Goldstein, David (NIH/NINDS); Snapper, Howard; Sabharwal, Rasna; Vera-Ellen Lucci

Subject: Re: [EXTERNAL] RE: AAS Board Meeting Minutes 04/17/19

While I think this looks nice, and I fully support the use of HPV vaccine, I wonder if this is going too far in terms of what the AAS as an organization should do? This looks like an HPV advertisement to me, which goes beyond the message of the article.

Wolfgang

On May 17, 2019, at 7:03 PM, Victoria Claydon <victoria_claydon@sfu.ca> wrote:

Dear All,

You will recall that in our recent call we discussed preparing a lay infographic to accompany the HPV statement. Vera and I have worked with our local KT people at SFU to develop a simple

visual that hopefully captures the key message from a lay perspective, with clear and simple imagery and gender neutral appeal. We had a focus group here on Monday with community member feedback and this is the design that they wanted. I'd love to hear your thoughts – please feel free to share widely with patients and community members and solicit their feedback. The goal would be to disseminate it online and with key stakeholder groups. Once the article is published the link to the AAS website would be instead be a link to the manuscript. I believe Satish is going to look into whether it the paper can be made open access to facilitate widespread dissemination.

Best wishes, Vic

<HPV Info Postcard.V4.2019 05 17.pdf>

From: Cheshire, William P., M.D.
Sent: Wed, 22 May 2019 16:58:12 +0000
To: 'Satish Raj'; Singer, Wolfgang, M.D.; Victoria Claydon
Cc: Amber Millen; Steven Vernino <Steven.; Chelimsky, Gisela; Norcliffe-Kaufmann, Lucy; Shibao, Cyndya; Goldstein, David (NIH/NINDS) [E]; Snapper, Howard; Sabharwal, Rasna; Vera-Ellen Lucci
Subject: RE: [EXTERNAL] RE: RE: AAS Board Meeting Minutes 04/17/19

I think it is too promotional – my intent was to suggest a better strategy.

From: Satish Raj [mailto:satish.raj@ucalgary.ca]
Sent: Wednesday, May 22, 2019 12:44 PM
To: Cheshire, William P., M.D.; Singer, Wolfgang, M.D.; Victoria Claydon
Cc: Amber Millen; Steven Vernino <Steven.; Chelimsky, Gisela; Norcliffe-Kaufmann, Lucy; Shibao, Cyndya; Goldstein, David (NIH/NINDS); Snapper, Howard; Sabharwal, Rasna; Vera-Ellen Lucci
Subject: [EXTERNAL] RE: RE: AAS Board Meeting Minutes 04/17/19

Bill,

I think that additional ways of Knowledge Dissemination such as YouTube would be great.

What we need acutely are thoughts from those that feel that this infographic is too promotional of the vaccine on ways to re-message it to deliver the ideal message.

Thoughts?

Satish

From: Cheshire, William P., M.D. <cheshire@mayo.edu>
Sent: May 22, 2019 9:07 AM
To: Singer, Wolfgang, M.D. <Singer.Wolfgang@mayo.edu>; Victoria Claydon <victoria_claydon@sfu.ca>
Cc: Amber Millen <amber@americanautonomicsociety.org>; Satish Raj <satish.raj@ucalgary.ca>; Steven Vernino <Steven. <Steven.Vernino@utsouthwestern.edu>; Chelimsky, Gisela <gchelimsky@mcw.edu>; Norcliffe-Kaufmann, Lucy <Lucy.Norcliffe-Kaufmann@nyumc.org>; Shibao, Cyndya <cyndya.shibao@vanderbilt.edu>; Goldstein, David (NIH/NINDS) <goldsteind@ninds.nih.gov>; Snapper, Howard <Howard.Snapper@wellstar.org>; Sabharwal, Rasna <rasna-sabharwal@uiowa.edu>; Vera-Ellen Lucci <vlucci@sfu.ca>
Subject: RE: [EXTERNAL] RE: AAS Board Meeting Minutes 04/17/19

I agree with Wolfgang and think that the infographic oversimplifies the issue and appears too promotional.

Another strategy could be to produce an educational YouTube video with 1-3 AAS members having a conversation about this topic and addressing FAQs.

From: Singer, Wolfgang, M.D.

Sent: Friday, May 17, 2019 11:40 PM

To: Victoria Claydon

Cc: Amber Millen; Satish Raj; Cheshire, William P., M.D.; Steven Vernino <Steven.; Chelimsky, Gisela; Norcliffe-Kaufmann, Lucy; Shibao, Cyndya; Goldstein, David (NIH/NINDS); Snapper, Howard; Sabharwal, Rasna; Vera-Ellen Lucci

Subject: Re: [EXTERNAL] RE: AAS Board Meeting Minutes 04/17/19

While I think this looks nice, and I fully support the use of HPV vaccine, I wonder if this is going too far in terms of what the AAS as an organization should do? This looks like an HPV advertisement to me, which goes beyond the message of the article.

Wolfgang

On May 17, 2019, at 7:03 PM, Victoria Claydon <victoria_claydon@sfu.ca> wrote:

Dear All,

You will recall that in our recent call we discussed preparing a lay infographic to accompany the HPV statement. Vera and I have worked with our local KT people at SFU to develop a simple visual that hopefully captures the key message from a lay perspective, with clear and simple imagery and gender neutral appeal. We had a focus group here on Monday with community member feedback and this is the design that they wanted. I'd love to hear your thoughts – please feel free to share widely with patients and community members and solicit their feedback. The goal would be to disseminate it online and with key stakeholder groups. Once the article is published the link to the AAS website would be instead be a link to the manuscript. I believe Satish is going to look into whether it the paper can be made open access to facilitate widespread dissemination.

Best wishes, Vic

<HPV Info Postcard.V4.2019 05 17.pdf>

From: Amber Millen
Sent: Mon, 20 May 2019 12:52:33 -0700
To: Satish Raj; Steven Vernino; Cheshire, William P.; Singer, Wolfgang; Chelimsky, Gisela; Shibao, Cyndya; Norcliffe-Kaufmann, Lucy; Snapper, Howard; Victoria Claydon; Goldstein, David (NIH/NINDS) [E]
Subject: AAS Board minutes and message from Satish
Attachments: AAS BoD Meeting Minutes 2019May15.pdf

Hi all,

Attached are the minutes from last week's AAS Board call. Also, please see below for a message from Satish.

Cheers,
Amber

Amber Millen | Executive Director, American Autonomic Society
9500 Gilman Drive | BSB 5006, MC 0629 | La Jolla, CA 92093-0629 | USA
E: amber@americanautonomicsociety.org | T: (858) 534-3865 | F: (858) 534-1445
www.americanautonomicsociety.org | Follow us: @AASAutonomic



Colleagues,

I want to thank those of you who have been making time to attend our AAS Board Calls. I appreciate the time, efforts and insights that you provide.

I recognize that not all of us can make every meeting. Our schedules will simply not allow this.

I would ask that you make every effort to attend the Board Calls. If this is not possible, then I would ask that you email Amber in advance (ideally at least 24-48h in advance) to indicate that you are not able to make it. Your presence (either individually or combined with others) may cause us to be able to properly discuss (or not) some issues.

Thank you,
Satish

American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, May 15, 2019 (5pm EDT; 2pm PDT)

(b)(4)



American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, May 15, 2019 (5pm EDT; 2pm PDT)

(b)(4)



American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, May 15, 2019 (5pm EDT; 2pm PDT)

(b)(4)



American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, May 15, 2019 (5pm EDT; 2pm PDT)

(b)(4)



From: Goldstein, David (NIH/NINDS) [E]
Sent: Sat, 18 May 2019 16:19:51 -0400
To: Steven Vernino; Victoria Claydon; 'Amber Millen'; 'Satish Raj'; 'Cheshire, William P.'; 'Singer, Wolfgang'; 'Chelimsky, Gisela'; 'Norcliffe-Kaufmann, Lucy'; 'Shibao, Cyndya'; 'Snapper, Howard'; 'Sabharwal, Rasna'; 'Vera-Ellen Lucci'
Subject: Re: AAS Board Meeting Minutes 04/17/19

Steve hits the nail on the head.

David S. Goldstein, MD PhD
Chief, Autonomic Medicine Section
(formerly Clinical Neurocardiology Section)
CNP/DIR/NINDS/NIH
9000 Rockville Pike
Bldg. 10 Rm. 8N260
Bethesda, MD 20892-1620
Phone: 301-496-2103
iPhone: (b)(6)
Fax: 301-402-0180

email: goldsteind@ninds.nih.gov

Open Autonomics Clinical Fellow slot! E-mail Dr. Goldstein for info.

To download Dr. Goldstein's e-book, *Principles of Autonomic Medicine*, visit
<https://neuroscience.nih.gov/ninds/Faculty/Profile/david-goldstein.aspx> Selected Publications.
Check out <https://www.youtube.com/watch?v=qGQ4KDCYLSU> & learn about our
new NAC/PD study!

From: Steven Vernino <Steven.Vernino@UTSouthwestern.edu>
Date: Saturday, May 18, 2019 at 4:18 PM
To: Victoria Claydon <victoria_claydon@sfu.ca>, 'Amber Millen' <amber@americanautonomicsociety.org>, Satish Raj <satish.raj@ucalgary.ca>, "Cheshire, William P." <cheshire@mayo.edu>, "Singer, Wolfgang" <Singer.Wolfgang@mayo.edu>, "Chelimsky, Gisela" <gchelimsky@mcw.edu>, "Norcliffe-Kaufmann, Lucy" <Lucy.Norcliffe-Kaufmann@nyumc.org>, "Shibao, Cyndya" <cyndya.shibao@Vanderbilt.Edu>, David Goldstein <goldsteind@ninds.nih.gov>, "Snapper, Howard" <Howard.Snapper@wellstar.org>, "Sabharwal, Rasna" <rasna-sabharwal@uiowa.edu>, 'Vera-Ellen Lucci' <vlucci@sfu.ca>
Subject: Re: AAS Board Meeting Minutes 04/17/19

It looks nice but I agree with Wolfgang that this looks like a promotional/informational piece for the CDC and very pro-vaccine

Something from AAS should focus on "what is dysautonomia?" and "the evidence currently does not establish a causative link between HPV vaccine and dysautonomia".

One could argue that the possibility of dysautonomia after vaccination hasn't been completely excluded. It is probably impossible to exclude this possibility entirely but the incidence of autonomic complications of vaccination appears to be very small

From: Victoria Claydon <victoria_claydon@sfu.ca>

Sent: Friday, May 17, 2019 7:02 PM

To: 'Amber Millen'; 'Satish Raj'; 'Cheshire, William P.'; 'Singer, Wolfgang'; Steven Vernino; 'Chelimsky, Gisela'; 'Norcliffe-Kaufmann, Lucy'; 'Shibao, Cyndya'; 'Goldstein, David (NIH/NINDS)'; 'Snapper, Howard'; 'Sabharwal, Rasna'; 'Vera-Ellen Lucci'

Subject: RE: AAS Board Meeting Minutes 04/17/19

Dear All,

You will recall that in our recent call we discussed preparing a lay infographic to accompany the HPV statement. Vera and I have worked with our local KT people at SFU to develop a simple visual that hopefully captures the key message from a lay perspective, with clear and simple imagery and gender neutral appeal. We had a focus group here on Monday with community member feedback and this is the design that they wanted. I'd love to hear your thoughts – please feel free to share widely with patients and community members and solicit their feedback. The goal would be to disseminate it online and with key stakeholder groups. Once the article is published the link to the AAS website would be instead be a link to the manuscript. I believe Satish is going to look into whether it the paper can be made open access to facilitate widespread dissemination.

Best wishes, Vic

UT Southwestern
Medical Center
The future of medicine, today.

From: Shibao, Cyndya
Sent: Sat, 18 May 2019 16:25:33 +0000
To: Victoria Claydon; 'Amber Millen'; 'Satish Raj'; 'Cheshire, William P.'; 'Singer, Wolfgang'; 'Steven Vernino <Steven.>'; 'Chelimsky, Gisela'; 'Norcliffe-Kaufmann, Lucy'; Shibao, Cyndya A (University); Goldstein, David (NIH/NINDS) [E]; 'Snapper, Howard'; 'Sabharwal, Rasna'; 'Vera-Ellen Lucci'
Subject: Re: AAS Board Meeting Minutes 04/17/19

I think this is a great idea and be very useful in our clinic to rapidly disseminate the information. I will pass it along to the rest of the Vanderbilt team including our NP for feedback and vaccine safety network surveillance system at Vandy.

I have a couple of comments. We usually use center for disease control, and not centres. Not sure if this a typo.

Could the title be more direct. What you need to know about HPV vaccine and Dysautonomia and POTS.

Love the color and the graphics.

Thank you Vic! . This is a wonderful work.

Cyndya

Get [Outlook for iOS](#)

From: Victoria Claydon <victoria_claydon@sfu.ca>
Sent: Friday, May 17, 2019 7:05 PM
To: 'Amber Millen'; 'Satish Raj'; 'Cheshire, William P.'; 'Singer, Wolfgang'; 'Steven Vernino <Steven.>'; 'Chelimsky, Gisela'; 'Norcliffe-Kaufmann, Lucy'; Shibao, Cyndya A (University); 'Goldstein, David (NIH/NINDS)'; 'Snapper, Howard'; 'Sabharwal, Rasna'; 'Vera-Ellen Lucci'
Subject: RE: AAS Board Meeting Minutes 04/17/19

Dear All,

You will recall that in our recent call we discussed preparing a lay infographic to accompany the HPV statement. Vera and I have worked with our local KT people at SFU to develop a simple visual that hopefully captures the key message from a lay perspective, with clear and simple imagery and gender neutral appeal. We had a focus group here on Monday with community member feedback and this is the design that they wanted. I'd love to hear your thoughts – please feel free to share widely with patients and community members and solicit their feedback. The goal would be to disseminate it online and with key stakeholder groups. Once the article is published the link to the AAS website would be instead be a link to the manuscript. I believe Satish is going to look into whether it the paper can be made open access to facilitate widespread dissemination.

Best wishes, Vic

From: Snapper, Howard
Sent: Sat, 18 May 2019 13:49:24 +0000
To: Victoria Claydon
Cc: Amber Millen; Satish Raj; Cheshire, William P.; Singer, Wolfgang; Steven Vernino <Steven.; Chelimsky, Gisela; Norcliffe-Kaufmann, Lucy; Shibao, Cyndya; Goldstein, David (NIH/NINDS) [E]; Sabharwal, Rasna; Vera-Ellen Lucci
Subject: Re: **[**WARNING** EXTERNAL MAIL]** RE: AAS Board Meeting Minutes 04/17/19

I like it! Great message!

Sent from my iPhone

On May 17, 2019, at 8:04 PM, Victoria Claydon <victoria_claydon@sfu.ca> wrote:

Dear All,

You will recall that in our recent call we discussed preparing a lay infographic to accompany the HPV statement. Vera and I have worked with our local KT people at SFU to develop a simple visual that hopefully captures the key message from a lay perspective, with clear and simple imagery and gender neutral appeal. We had a focus group here on Monday with community member feedback and this is the design that they wanted. I'd love to hear your thoughts – please feel free to share widely with patients and community members and solicit their feedback. The goal would be to disseminate it online and with key stakeholder groups. Once the article is published the link to the AAS website would be instead be a link to the manuscript. I believe Satish is going to look into whether it the paper can be made open access to facilitate widespread dissemination.

Best wishes, Vic

<HPV Info Postcard.V4.2019 05 17.pdf>

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From: Victoria Claydon
Sent: Fri, 17 May 2019 17:02:26 -0700
To: 'Amber Millen'; 'Satish Raj'; 'Cheshire, William P.'; 'Singer, Wolfgang'; 'Steven Vernino <Steven.>'; 'Chelimsky, Gisela'; 'Norcliffe-Kaufmann, Lucy'; 'Shibao, Cyndya'; Goldstein, David (NIH/NINDS) [E]; 'Snapper, Howard'; 'Sabharwal, Rasna'; 'Vera-Ellen Lucci'
Subject: RE: AAS Board Meeting Minutes 04/17/19
Attachments: HPV Info Postcard.V4.2019 05 17.pdf

Dear All,

You will recall that in our recent call we discussed preparing a lay infographic to accompany the HPV statement. Vera and I have worked with our local KT people at SFU to develop a simple visual that hopefully captures the key message from a lay perspective, with clear and simple imagery and gender neutral appeal. We had a focus group here on Monday with community member feedback and this is the design that they wanted. I'd love to hear your thoughts – please feel free to share widely with patients and community members and solicit their feedback. The goal would be to disseminate it online and with key stakeholder groups. Once the article is published the link to the AAS website would be instead be a link to the manuscript. I believe Satish is going to look into whether it the paper can be made open access to facilitate widespread dissemination.

Best wishes, Vic

HPV vaccination: what I need to know

Obtained by ICANdecide.org via FOIA

7 CANCERS PREVENTED

Several cancers are prevented by getting the HPV* vaccination: anus, vulva, vagina, penis, mouth, oropharynx, cervix.

*Human papilloma virus



VACCINE IS SAFE

Over **270 million** people have been vaccinated with **no** patterns of adverse events found. Researchers have found **no** evidence that HPV vaccination causes problems controlling blood pressure and heart rate (e.g. dysautonomia or POTS).



FOR ALL YOUTH

The HPV vaccine is for all youth. The Centres for Disease Control and Prevention recommends routine vaccination of boys **and** girls aged 11-12 years.

For more information see the AAS position statement:
americanautonomicsociety.org

From: Amber Millen
Sent: Wed, 15 May 2019 12:18:08 -0700
To: Satish Raj; Steven Vernino; Cheshire, William P.; Singer, Wolfgang; Chelimsky, Gisela; Shibao, Cyndya; Norcliffe-Kaufmann, Lucy; Goldstein, David (NIH/NINDS) [E]; Snapper, Howard; Victoria Claydon
Subject: Re: AAS Board Meeting, Wednesday, May 15 - Agenda and docs
Attachments: AAS BoD Meeting Agenda 2019May15.docx, AAS G Suite Proposal[2].pdf

Hi all,

Attached is an updated agenda with an additional item and document included to discuss today, time permitting.

Cheers,
Amber

From: Amber Millen <amber@americanautonomicsociety.org>
Date: Tuesday, May 14, 2019 at 5:31 PM
To: Satish Raj <satish.raj@ucalgary.ca>, Steven Vernino <Steven.Vernino@UTSouthwestern.edu>, "Cheshire, William P." <cheshire@mayo.edu>, "Singer, Wolfgang" <Singer.Wolfgang@mayo.edu>, "Chelimsky, Gisela" <gchelimsky@mcw.edu>, "Shibao, Cyndya" <cyndya.shibao@Vanderbilt.Edu>, "Norcliffe-Kaufmann, Lucy" <Lucy.Norcliffe-Kaufmann@nyumc.org>, "Goldstein, David (NIH/NINDS)" <goldsteind@ninds.nih.gov>, "Snapper, Howard" <Howard.Snapper@wellstar.org>, Victoria Claydon <victoria_claydon@sfu.ca>
Subject: AAS Board Meeting, Wednesday, May 15 - Agenda and docs

Hi all,

Attached is an agenda for tomorrow's conference call.

Also attached is the document (and email below) related to the TDP video project to be discussed.

Also attached is some information on two hotels in Hawaii we are considering for the 2020 meeting. These have been selected from a list of over 10 hotels and seem to be the best options for our needs and price range. Both hotels have similar catering costs, so the final F&B will be similar. The room rates are higher for Maui so it would be slightly more expensive for the attendees than Kona, but Maui has offered some concessions that better benefit the AAS (particularly the better breakfast at \$30 per person, AV discount, etc).

Call in details are below:

AAS BOARD MONTHLY CONFERENCE CALL

Wednesday, May 15, 2 pm Pacific / 3 pm Mountain / 4 pm Central / 5 pm Eastern

US: (b)(6)

Canada (b)(6)

Meeting ID: (b)(6)

International numbers available: (b)(6)

Cheers,
Amber

Amber Millen | Executive Director, American Autonomic Society
9500 Gilman Drive | BSB 5006, MC 0629 | La Jolla, CA 92093-0629 | USA
E: amber@americanautonomicsociety.org | T: (858) 534-3865 | F: (858) 534-1445
www.americanautonomicsociety.org | Follow us: @AASAutonomic



From: Amber Millen <amber@americanautonomicsociety.org>
Date: Wednesday, May 8, 2019 at 2:15 PM
To: Satish Raj <satish.raj@ucalgary.ca>, Steven Vernino <Steven.Vernino@UTSouthwestern.edu>, "Cheshire, William P." <cheshire@mayo.edu>, "Singer, Wolfgang" <Singer.Wolfgang@mayo.edu>, "Chelimsky, Gisela" <gchelimsky@mcw.edu>, "Shibao, Cyndya" <cyndya.shibao@Vanderbilt.Edu>, "Norcliffe-Kaufmann, Lucy" <Lucy.Norcliffe-Kaufmann@nyumc.org>, "Goldstein, David (NIH/NINDS)" <goldsteind@ninds.nih.gov>, "Snapper, Howard" <Howard.Snapper@wellstar.org>, Victoria Claydon <victoria_claydon@sfu.ca>
Subject: FW: AAS/TDP Video Project

Hi all,

Please see below for a message from Steve regarding the TDP video project. We will discuss at next Wednesday's board meeting.

Cheers,
Amber

Amber Millen | Executive Director, American Autonomic Society
9500 Gilman Drive | BSB 5006, MC 0629 | La Jolla, CA 92093-0629 | USA
E: amber@americanautonomicsociety.org | T: (858) 534-3865 | F: (858) 534-1445
www.americanautonomicsociety.org | Follow us: @AASAutonomic

From: Steven Vernino <Steven.Vernino@UTSouthwestern.edu>
Date: Wednesday, May 8, 2019 at 12:58 PM
To: Amber Millen <amber@americanautonomicsociety.org>, "satish.raj@ucalgary.ca" <satish.raj@ucalgary.ca>, "Christopher H. Gibbons" <cgibbons@bidmc.harvard.edu>
Subject: Fwd: AAS/TDP Video Project

Amber,

This is the draft document that TDP provided today during our call. The majority the points are reasonable. I think we can clarify a few things around ownership of the content and sponsorship. One of the big questions that came up was around space for the building of video segments during the meeting. From what I understand, they've decided not to have a allied health symposium on Saturday, but instead, would like us to help secure them a room for the video taping. We will have to include that additional expense in their commitment to the project

Amber, please send this document around to the board and put it on the agenda for our next meeting which hopefully is soon. I want to see if there are still major sticking points. I made it clear that AAS Will own the content . They proposed to host the content on an external server but will provide autonomic society delegate with administrative access to control the availability of the content.

We really don't have a legal document here, but I think it will be binding if both the AAS and TDP Boards are signed off on it.

Sent from my iPhone

Begin forwarded message:

From: Jennifer Walsh <Jennifer@thedysautonomiaproject.org>

Date: May 8, 2019 at 3:10:08 PM EDT

To: "Nate Freeman (N.Freeman@networkpeople.com)" <N.Freeman@networkpeople.com>, "Kelly Freeman (K.Freeman@networkpeople.com)" <K.Freeman@networkpeople.com>, Amber Millen <amber@americanautonomicsociety.org>, "satish.raj@ucalgary.ca" <satish.raj@ucalgary.ca>, "steven.vernino@utsouthwestern.edu" <steven.vernino@utsouthwestern.edu>

Subject: AAS/TDP Video Project

Good afternoon all,

Attached is a document regarding the upcoming video project with AAS and TDP.

Thank you,
Jennifer

UT Southwestern
Medical Center
The future of medicine, today.

American Autonomic Society Board of Directors – Meeting Agenda
Wednesday, April 17, 2019 (5pm EDT; 2pm PDT)

(b)(4)



PROPOSAL

(b)(4)

(b)(4)

From: Amber Millen
Sent: Wed, 17 Apr 2019 17:03:28 -0700
To: Satish Raj; Cheshire, William P.; Singer, Wolfgang; Steven Vernino <Steven.; Chelimsky, Gisela; Norcliffe-Kaufmann, Lucy; Shibao, Cyndya; Goldstein, David (NIH/NINDS) [E]; Snapper, Howard; Victoria Claydon; Sabharwal, Rasna; Vera-Ellen Lucci
Subject: AAS Board Meeting Minutes 04/17/19
Attachments: AAS BoD Meeting Minutes 2019Apr17 FINAL.pdf

Here are the minutes from today's Board conference call.

Amber Millen, Executive Director
American Autonomic Society
9500 Gilman Drive, BSB 5006, MC 0629
La Jolla, CA 92093-0629 USA
Office (858) 534-3865, Fax (858) 534-1445
Email: amber@americanautonomicsociety.org
Website: <http://americanautonomicsociety.org/>

American Autonomic Society Board of Directors – Meeting Minutes
Wednesday, April 17, 2019 (5pm EDT; 2pm PDT)

(b)(4)



American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, April 17, 2019 (5pm EDT; 2pm PDT)

(b)(4)



American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, April 17, 2019 (5pm EDT; 2pm PDT)

(b)(4)



American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, April 17, 2019 (5pm EDT; 2pm PDT)

(b)(4)



American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, April 17, 2019 (5pm EDT; 2pm PDT)

(b)(4)



American Autonomic Society Board of Directors – Meeting Minutes

Wednesday, April 17, 2019 (5pm EDT; 2pm PDT)

(b)(4)



From: Kaufmann, Horacio
Sent: Wed, 20 Feb 2019 20:26:06 +0000
To: Satish Raj; Chris Gibbons; Italo Biaggioni; Mark Chapleau; Thomas Chelimsky; Gisela Chelimsky; William Cheshire; Roy Freeman; Benarroch, Eduardo E., M.D.; Felicia Axelrod; Goldstein, David (NIH/NINDS) [E]; Michael Joyner; Norcliffe-Kaufmann, Lucy; Phillip Low; David Robertson; Rose Robertson; Cyndya Shibao; Wolfgang Singer; Steven Vernino
Cc: Alex Barboi; Amber Millen
Subject: Re: AAS HPV Vaccine Statement

Timely and very relevant.

Thanks for doing this.

Best,

H

From: Satish Raj <satish.raj@ucalgary.ca>
Sent: Tuesday, February 19, 2019 8:57:42 PM
To: Chris Gibbons; Italo Biaggioni; Mark Chapleau; Thomas Chelimsky; Gisela Chelimsky; William Cheshire; Roy Freeman; Benarroch, Eduardo E., M.D.; Felicia Axelrod; David Goldstein; Michael Joyner; Kaufmann, Horacio; Norcliffe-Kaufmann, Lucy; Phillip Low; David Robertson; Rose Robertson; Cyndya Shibao; Wolfgang Singer; Steven Vernino
Cc: Alex Barboi; Amber Millen
Subject: AAS HPV Vaccine Statement

Colleagues,

Attached is a draft of our AAS HPV Vaccine Statement after some fine-tuning. The underlying message has not changed. Hopefully the argument reads in a cogent and reasoned manner.

Please review this draft. Please confirm your approval and ongoing willingness to be a co-author on this, confirm your disclosures and add in any funding that you wish listed. We do not expect that any grant directly funded this work. However, some funding/grants may have provided salary support.

Please get these back to me by the end of this coming weekend.

If I do not hear from you, I will assume an ongoing ringing endorsement and no changes to the disclosures or funding support.

Our plan is to pursue a joint publication in *Clinical Autonomic Research* and *Autonomic Neurosciences: Basic & Clinical*.

Thank you,

Satish

This email message, including any attachments, is for the sole use of the intended recipient(s) and may contain information that is proprietary, confidential, and exempt from disclosure under applicable law. Any unauthorized review, use, disclosure, or distribution is prohibited. If you have received this email in error please notify the sender by return email and delete the original message. Please note, the recipient should check this email and any attachments for the presence of viruses. The organization accepts no liability for any damage caused by any virus transmitted by this email.
=====

From: Satish Raj
Sent: Wed, 20 Feb 2019 20:17:47 +0000
To: Low, Phillip A., M.D.; Chris Gibbons; Italo Biaggioni; Mark Chapleau; Thomas Chelimsky; Gisela Chelimsky; Cheshire, William P., M.D.; Roy Freeman; Benarroch, Eduardo E., M.D.; Felicia Axelrod; Goldstein, David (NIH/NINDS) [E]; Joyner, Michael J., M.D.; Horacio Kaufmann; Lucy Kaufmann; David Robertson; Rose Robertson; Cyndya Shibao; Singer, Wolfgang, M.D.; Steven Vernino
Cc: Alex Barboi; Amber Millen
Subject: RE: AAS HPV Vaccine Statement

Thank you Phillip.

Satish

From: Low, Phillip A., M.D. <low@mayo.edu>
Sent: Wednesday, February 20, 2019 12:03 PM
To: Satish Raj <satish.raj@ucalgary.ca>; Chris Gibbons <cgibbons@bidmc.harvard.edu>; Italo Biaggioni <italo.biaggioni@vumc.org>; Mark Chapleau <mark-chapleau@uiowa.edu>; Thomas Chelimsky <tchelimsky@mcw.edu>; Gisela Chelimsky <gchelimsky@mcw.edu>; Cheshire, William P., M.D. <cheshire@mayo.edu>; Roy Freeman <rfeeman@bidmc.harvard.edu>; Benarroch, Eduardo E., M.D. <benarroch@mayo.edu>; Felicia Axelrod <Faxelrod@rcn.com>; David Goldstein <goldsteind@ninds.nih.gov>; Joyner, Michael J., M.D. <joyner.michael@mayo.edu>; Horacio Kaufmann <Horacio.Kaufmann@nyumc.org>; Lucy Kaufmann <norcll01@nyumc.org>; David Robertson <david.robertson@vanderbilt.edu>; Rose Robertson <rosemarie.robertson@heart.org>; Cyndya Shibao <cyndya.shibao@vumc.org>; Singer, Wolfgang, M.D. <Singer.Wolfgang@mayo.edu>; Steven Vernino <Steven.Vernino@UTSouthwestern.edu>
Cc: Alex Barboi <ABarboi@northshore.org>; Amber Millen <amber@americanautonomicsociety.org>
Subject: RE: AAS HPV Vaccine Statement

Had a quick read through. Very important and timely document.
Phillip

From: Satish Raj [<mailto:satish.raj@ucalgary.ca>]
Sent: Tuesday, February 19, 2019 7:58 PM
To: Chris Gibbons; Italo Biaggioni; Mark Chapleau; Thomas Chelimsky; Gisela Chelimsky; Cheshire, William P., M.D.; Roy Freeman; Benarroch, Eduardo E., M.D.; Felicia Axelrod; David Goldstein; Joyner, Michael J., M.D.; Horacio Kaufmann; Lucy Kaufmann; Low, Phillip A., M.D.; David Robertson; Rose Robertson; Cyndya Shibao; Singer, Wolfgang, M.D.; Steven Vernino
Cc: Alex Barboi; Amber Millen
Subject: [EXTERNAL] AAS HPV Vaccine Statement

Colleagues,

Attached is a draft of our AAS HPV Vaccine Statement after some fine-tuning. The underlying message has not changed. Hopefully the argument reads in a cogent and reasoned manner.

Please review this draft. Please confirm your approval and ongoing willingness to be a co-author on this, confirm your disclosures and add in any funding that you wish listed. We do not expect that any grant directly funded this work. However, some funding/grants may have provided salary support.

Please get these back to me by the end of this coming weekend.

If I do not hear from you, I will assume an ongoing ringing endorsement and no changes to the disclosures or funding support.

Our plan is to pursue a joint publication in *Clinical Autonomic Research* and *Autonomic Neurosciences: Basic & Clinical*.

Thank you,

Satish

From: Satish Raj
Sent: Wed, 20 Feb 2019 01:57:42 +0000
To: Chris Gibbons; Italo Biaggioni; Mark Chapleau; Thomas Chelimsky; Gisela Chelimsky; William Cheshire; Roy Freeman; Benarroch, Eduardo E., M.D.; Felicia Axelrod; Goldstein, David (NIH/NINDS) [E]; Michael Joyner; Horacio Kaufmann; Lucy Kaufmann; Phillip Low; David Robertson; Rose Robertson; Cyndya Shibao; Wolfgang Singer; Steven Vernino
Cc: Alex Barboi; Amber Millen
Subject: AAS HPV Vaccine Statement
Attachments: AAS HPV Vaccine Alex Dec 2019Feb19.docx

Colleagues,

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Thank you,

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Human papilloma vaccine (HPV) and Autonomic Disorders: A Position Statement from the American Autonomic Society

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I. Impact of human papilloma virus on human health

Human papillomaviruses (HPV) are non-enveloped viruses with a double-stranded circular DNA genome. The genome is enclosed in an icosahedral capsid, which is made up of two proteins: the major capsid protein (L1) and the minor capsid protein (L2). HPV is the most common sexually transmitted infection in the United States. An estimated 14 million persons are newly infected with HPV each year in the US with nearly half occurring in adolescents and young adults¹. Although infection is common (80% of women become infected HPV biology) and men have higher susceptibility to HPV infections than women², most infections are cleared by a cell mediated immune response³.

Epidemiological data supports the existence of a group of high-risk human papilloma viruses associated with cancer: HPV types 16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58 and 59^{3,4}. These high-risk viruses cause dysfunction of cell cycle regulators and cause neoplasia^{3,5}. Inability of the immune system to clear this high risk infection is another hypothesized pathway leading to cancer⁶. HPV infection causes cancers at transformation zones between different kinds of epithelium: cervix, anus, oropharynx⁷. In addition to oncogenic HPV infection, concomitant sexually transmitted diseases, multiparity, smoking, hormonal contraception are other identified risk factors for cervical cancer⁷. There is a severity dependent infection prevalence: HPV is positive in 11.7% with normal cervical cytology, 50-70% cervical intraepithelial neoplasia (CIN) 1, 85% in CIN 2, 90-100% in CIN 3, 85% of vaginal cancer, 80-96% of anal cancer, 40-70% of invasive penile cancer and 72% of squamous cell head and neck cancer^{3,4}.

Infection with HPV is recognized as one of the major causes of infection related cancer worldwide⁸. Persistent oncogenic HPV infections cause over 500,000 cancers worldwide and

30,000 cancers^{7,9,10} in the US annually, with more than half of those cases leading to death¹¹.

Cervical cancer is the fourth most common cancer in women and the second largest cause of mortality from cancer in the developing world¹¹⁻¹⁵. HPV also has a major role in the etiology of squamous cell carcinoma of the anus (men and women), vulva, vagina, penis, mouth and oropharynx¹⁶⁻¹⁸.

II. Current approach to treatment of HPV related diseases

Education, abstinence, condom use can all reduce infection risk, but even strict condom use is not completely protective in males⁷. Current treatments cannot eliminate HPV thus contributing to high infection prevalence⁴.

HPV vaccination is effective in prevention of infection and prevention of high-grade precancerous lesions^{7,19}. Phase III randomized controlled trials of prophylactic HPV vaccination were designed to prevent incident related HPV infection and thus pre-neoplastic lesions^{20,21}. All vaccines demonstrated high immunogenicity and efficacy in preventing persistent infection (90% infection reduction, 90% reduction in genital warts) and precancerous (CIN3) lesions (85% reduction)²⁰. This makes HPV vaccination a high value public health intervention⁸.

Three HPV vaccines licensed in the US (Cervarix, Gardasil and Gardasil-9) protect against infection with HPV types 16 and 18 which cause over 60% of cervical and oropharyngeal HPV-related cancers. In addition, quadrivalent (Gardasil) and nonavalent (Gardasil 9) HPV vaccines protect against HPV types 6 and 11, which cause 90% of genital warts, and Gardasil 9 protects against five additional oncogenic HPV serotypes. These vaccines are composed of virus-like particles (VLPs) derived from the major capsid protein (L1) of HPV, contain no genetic viral

material and are highly immunogenic. All three available vaccines are most effective in preventing HPV-related disease in naïve patients only and ideally should be administered before onset of sexual activity. The vaccines have no therapeutic effect in patients who already have genital lesions and HPV-related cancer¹⁹.

Based on phase III trial data, in 2006, the Advisory Committee on Immunization Practices (ACIP) of the Centers for Disease Control and Prevention (CDC), recommended routine vaccination of females 11–12 years of age and catch-up vaccination of females 13–26 years of age with a series of 3 doses of Gardasil given at baseline, 1–2 months after initiation, and 6 months after initiation¹³. Routine Gardasil vaccination of males 11–12 years of age, with catch-up vaccination of males 13–21 years of age, was recommended by the ACIP in 2011²². FDA licensed the nonavalent Gardasil vaccine in 2009 for females and in 2014 for males²³. Given the high immunogenicity of Gardasil among males (97.4-99.2% seroconversion at seven months)²⁴ and suboptimal vaccination coverage among females, HPV vaccination of males benefits females through herd immunity²³. Furthermore, HPV vaccination will play an important role in stemming the increasing incidence of HPV-related oropharyngeal cancers in males which is expected to exceed that of cervical cancer in the US by 2020²².

III. HPV vaccine safety

Population-based vaccination program implementation includes monitoring of coverage, impact and safety⁸. There are passive monitoring programs which have limitations, like incomplete reporting and coincidental associations. Because of this shortcoming, routine formal evaluations of the passive report systems are performed. There have been multiple

post-licensure vaccine safety evaluations, independent of the manufacturers, both in the US and internationally⁸. In addition, comprehensive, independent scientific reviews have been conducted to assess the safety of the HPV vaccines^{25,26}.

The most common adverse events associated with HPV vaccines (as a group) reported in the literature are injection site related: local pain, redness, swelling. Reported systemic side effects include: fatigue, fever, GI symptoms (diarrhea, nausea, vomiting), headache, myalgia and arthralgia^{19,22,27,28}. Syncope is a manageable side effect of vaccination in general and simple measures can be adopted to avoid it²⁶. All reported symptoms are transient and do not worsen with subsequent vaccine doses. To date, the data from clinical trials and available post-marketing periodic safety updates have indicated acceptable safety of HPV vaccines. In fact systemic side effects did not differ between vaccinated and placebo groups for bivalent, quadrivalent and nonavalent vaccines and there is no increased risk of death associated with HPV vaccination²⁶.

Data released by the Global Advisory Committee on Vaccine Safety (GACVS) in June 2017²⁹ included a safety update on HPV vaccines. Since licensure in 2006, over 270 million doses of HPV vaccines have been distributed. The committee evaluated safety data for this vaccine in 2007, 2008, 2009, 2013, 2014, and 2015. Evaluation of large population-based data by the GACVS from multiple countries found no causal association between HPV vaccination and diverse symptoms that included chronic pain, motor dysfunction, complex regional pain syndrome (CRPS), or postural orthostatic tachycardia syndrome (POTS)²⁹.

A review of reports of POTS following HPV vaccination by the Vaccine Adverse Reporting system (VAERS), commissioned by the Centers for Disease Control and Prevention (CDC) and

the U.S. Food and Drug Administration (FDA) found approximately one POTS case for every 6.5 million worldwide distributed HPV vaccine doses (29 cases total) between 2006 and 2015. Twenty of these cases had a history of pre-existing medical conditions: chronic fatigue, asthma and chronic headaches. For this time period, the crude reporting rate of POTS after HPV vaccination was rare, measuring 0.07%³⁰.

To understand the association between HPV vaccination and autonomic and/or pain disorders, a large registry-based hospital study in Finland investigated the incidence of autonomic or pain disorders for the years 2002-2012, which were PRIOR to the introduction of the HPV vaccine in Finland. In 2002, there were 2 cases of POTS per 100,000 person-years, and this increased by 2012 to almost 13 cases of POTS per 100,000 years³¹. The investigators found that one cause for the higher annual incidence rate for POTS and chronic fatigue syndrome (CFS) was increased physician awareness of these diagnoses.

IV. Dissenting opinions regarding safety

Anecdotal reports alleging possible adverse events following HPV vaccination have been published³²⁻³⁹. Cited adverse events include: dysautonomia, CFS, CRPS, and POTS³⁸.

A presumed immunological or inflammatory response to vaccination is considered the linking mechanism to the development of POTS, pain syndrome or other form of dysautonomia³²⁻³⁹. In a review of these publications, several key factors are apparent:

1. Some of the reported cases labeled as post HPV vaccine POTS did not have a well-defined diagnosis^{36,37}, did not take into consideration effects of physical deconditioning on bedside testing³⁹ and clinical descriptions did not fit the accepted definition of POTS for both adolescents and children^{36,40}.

2. Overall, the number of reported or observed POTS cases after vaccination was generally lower compared to the expected incidence that would occur naturally in the target population under almost all assumptions for all regions and countries, except for Denmark where the majority of POTS cases that have been reported, come from one syncope unit^{41,42}.

3. Critical analysis of the Danish cohort study revealed a flawed scientific approach⁴². The Scientific Advisory Group of the European Medicines Agency investigated the Danish Syncope Unit Cohort in more detail and concluded: “this was a highly selected sample of patients, apparently chosen to fit a pre-specified hypothesis of vaccine-induced injury”⁴². All patients were referred to the same syncope unit for evaluation for an existing concern of HPV vaccine-induced illness, which makes the case series unrepresentative of the general population and there was no control group⁴¹. The methods used to ascertain the trigger and time to onset of specified symptoms of autonomic dysfunction may inherently have biased patient recall³⁰. There was no consistent relationship with the dose sequence to support the notion that this case series is suggestive of a specific autoimmune response to the vaccine⁴².

Despite having issues in case ascertainment and classification, unsuitable analytic methods and misleading conclusions²⁶, these case reports have drawn media attention to a small numbers of individuals with purported adverse reactions to HPV vaccination. The reports influence how providers communicate risks associated with not vaccinating^{43,44} are confounded by patient care-seeking behavior patterns pre- and post-vaccination⁴⁵, thus reducing the number of vaccinated individuals. In fact, the reports have created widespread fear, resulting in decreased vaccination rates or even dismantling of vaccination programs in some countries.^{31,46}

It is common for a diagnosis of any syndrome or disease, including a persistent autonomic or pain disorder, to be attributed to a recent life event such as a recent illness, trauma or even HPV vaccination^{25,26}. The fact that certain conditions peak in incidence at the same age, and in the same population that is being vaccinated (peri-pubertal males and females), is insufficient proof of causality, especially with chronic illness such as dysautonomia and POTS, which have relapsing-remitting courses and frequent exacerbations caused by a variety of factors. Attribution of causality requires solid epidemiological data demonstrating evidence for causality at the population level, with supporting evidence of biological plausibility^{47,48}.

V. American Autonomic Society Position

At this time, the American Autonomic Society (AAS) finds that the data do not support a causal relationship between HPV vaccination and CRPS, POTS, or other forms of dysautonomia. Large population studies and exposure of over 270 million people to the HPV vaccine have not resulted in an identifiable pattern of adverse events, and no evidence of an increase in dysautonomia or POTS with use of the vaccine.

The AAS acknowledges that several groups have dissenting opinions^{32-39 46}. However, the data at this time constitutes only weak temporal associations between events, and their hypothesized mechanisms have not been scientifically proven. The small sample sizes, inherent selection biases, and lack of control populations preclude drawing any scientifically valid conclusions of causality^{30,41,48}.

The American Autonomic Society recognizes that HPV increases the risk of cancer in patients who become infected. In the absence of compelling data for harm from vaccination,

we are concerned that isolated reports linking HPV vaccination to autonomic disorders or chronic pain disorders may cause needless panic in those at risk for HPV infection and decrease the rate of HPV vaccinations. Neglecting HPV vaccination has the potential for significant public harm by eliminating equitable protection from vaccination against HPV related cancer²⁶. For example, in Japan where HPV vaccination was not proactively recommended, mortality from cervical cancer increased by 3.4% between 2005 and 2015⁴³. In contrast, herd immunity seems to develop in countries with a vaccination rate greater than 50%, with an associated decline in cancer rates^{12,49}.

As with any reported autonomic disorder, the AAS supports ongoing surveillance and collection of data including the type and timing of symptom onset after vaccination, and the quality and objectively measured severity of potential autonomic adverse effects related to HPV vaccination^{23,31,45,50-56}. The AAS also supports ongoing, well-designed long-term population based epidemiological studies that assess the safety and efficacy of vaccines of any sort. However, the AAS warns against drawing premature conclusions from poorly designed trials or small cohort studies that do not adequately assess the risks and benefits of population level vaccination.

Funding

Conflicts Declaration

AB – None

WPC – None

CHG – C.H.G. has received research support at Beth Israel Deaconess Medical Center from Grifols Inc. C.H.G has served as a scientific consult for Lundbeck. C.H.G. has served as a consultant for the United States Department of Justice Vaccine Compensation Program.

CAS – C.A.S. received grant support from Office of Orphan Products Development, Food and Drug Administration, Grant #FD-R-04778-01-A3. C.A.S. has received speaker honorarium from Lundbeck Pharmaceuticals. C.A.S. received consulting honoraria from Lundbeck. CAS has received research support from the CDC, Clinical Immunization and Safety Assessment Program at Vanderbilt University Medical Center

LNK –

GC – Co-owner of PainStakers LLC

DSG – None

SV – Research support from Dysautonomia International.

WS – None

SRR – Consultant for GE Healthcare and Lundbeck LLC. Medicolegal consulting on diagnosis and causation of POTS.

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Subject: Re: AAS Board Meeting at 5 pm Eastern today

Save travels, Bill!

When in doubt, faint.

Dave

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To download Dr. Goldstein's e-book, *Principles of Autonomic Medicine*, visit <https://neuroscience.nih.gov/ninds/Faculty/Profile/david-goldstein.aspx> Selected Publications. Check out <https://www.youtube.com/watch?v=qGQ4KDCYLsU> & learn about our new NAC/PD study!

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Date: Wednesday, February 20, 2019 at 12:48 PM
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Cc: "Sabharwal, Rasna" <rasna-sabharwal@uiowa.edu>
Subject: RE: AAS Board Meeting at 5 pm Eastern today

Dear all,

With apologies, I will miss the board call this evening, as I am traveling to Thailand to give some lectures.

A few edits in the HPV draft are attached for your review. I approve of the document.

Our veterinarian on staff tells me that there are still wild tigers in Thailand, particularly in the jungles in the north, where I'll be. As a Princeton alumnus, I feel certain I would be comfortable around tigers, although if I encounter one that speaks the Thai language and not English, I would be at a disadvantage. The autonomic choice would be between maximal deployment of central command and sympathetic outflow versus activating the playing-dead response.

Bill