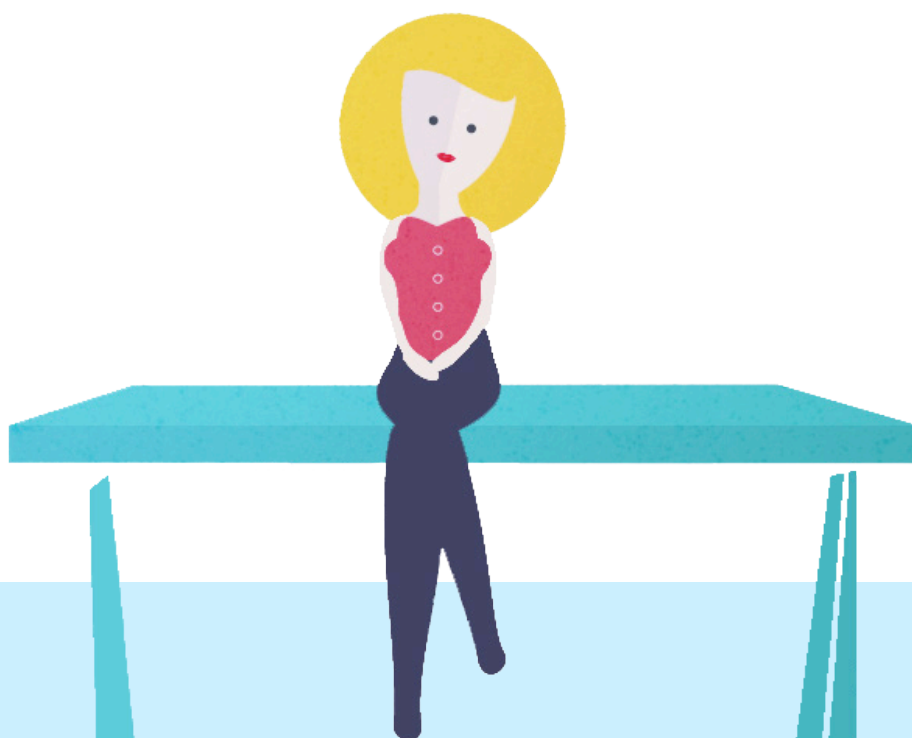


#ITSNOTINYOURHEAD

SOCIAL MEDIA CAMPAIGN REPORT



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BACKGROUND

EXECUTIVE SUMMARY

#ItsNotInYourHead is the name of a social media campaign about a chronic genital pain condition called Provoked Vestibulodynia, or PVD. The purpose of the campaign was to raise awareness about PVD, and in doing so break down the societal stigma that surrounds female genital pain. Furthermore, the campaign was centred on an educational video which was developed to share evidence from a recent clinical trial which found psychological treatment options were effective for managing symptoms of PVD¹. A targeted social media campaign was chosen as the medium to achieve widespread dissemination of the video and get it into the hands of women who can use the information. The campaign also partnered with digital marketing company, Ehm&Co in an effort to amplify the campaign messages to a broader audience.

The campaign, which ran for six months during October 2017-March 2018, was championed by Dr. Lori Brotto, a Canada Research Chair in women's sexual health, clinician, and executive director of the Women's Health Research Institute in Vancouver, BC, Canada. This report is a summary of how the #ItsNotInYourHead campaign came to be, the campaign activities, and the impact it had in mobilizing this new research evidence, and opening up the conversation about genital pain.

WHAT IS PVD?

Provoked Vestibulodynia, or PVD, is a type of localized vulvodynia (or pain in the vulva). The estimated prevalence of this condition is about 12% of the general population and approximately 20% of women under the age of 19.

PVD is characterized by intense pain provoked with direct contact to the vulvar vestibule (located at and around the entrance of the vagina). This can happen during sex, when attempting to use menstrual products, going for physical medical exams, wearing tight clothing, or even when sitting, to name a few examples.

Many women who live with PVD suffer in silence for years before receiving a diagnosis. The average length of time it takes to receive an accurate diagnosis spans 3-7 years, and that's with multiple visits to a variety of healthcare professionals. This is, unfortunately, due to the fact that PVD is difficult to diagnose based on a physical exam as there is no obvious sign of pain, infection, abrasions, or trauma – that is, the condition is typically not visible to the eye.

In addition to this, most of the symptoms (stabbing pain, burning, or itching) are similar to those of other common conditions, such as yeast infections, often leading to misdiagnosis or women being told that their pain is “all in their head”. This can lead to feelings of isolation, anxiety, depression, and distress. Moreover, women feel dismissed by their healthcare providers.

1 Brotto L. A., Bergeron S., Zdaniuk B., Driscoll M., Grabovac A., Sadownik L., Smith K. B., Basson R. (2019). A comparison of mindfulness-based cognitive therapy vs. cognitive behavioral therapy for the treatment of provoked vestibulodynia in a hospital clinic setting. *Journal of Sexual Medicine*.

JOURNEY TO THE #ITSNOTINYOURHEAD CAMPAIGN

THE COMFORT STUDY

COGNITIVE THERAPY OR MINDFULNESS FOR THE TREATMENT OF PVD

Thanks to funding from the Canadian Institutes for Health Research (CIHR), a multidisciplinary team at the University of British Columbia completed a clinical trial to compare Cognitive Behavioural Therapy (CBT) with Mindfulness Based Therapy as treatment for PVD. The study was called COMFORT for short. While CBT was already known to be effective for managing symptoms of PVD, this was the first comprehensive study evaluating mindfulness for this population of women. The trial revealed that both treatments were effective and lead to statistically and clinically meaningful improvements in sexual function, quality of life, and reduced genital pain. These outcomes were maintained when participants were interviewed at 6 months and 12 months follow-up.

THE #ITSNOTINYOURHEAD VIDEO

TRANSLATING STUDY FINDINGS

As part of our end-of-grant knowledge translation strategy we developed a two minute video titled #ItsNotInYourHead together with a media design partner, The Thinking Box (www.thinkingbox.com). We engaged patients with lived experience of PVD to help develop the video script and had a patient champion narrate it. The video depicts a woman suffering in silence with chronic genital pain until she is finally diagnosed with PVD and realizes that she is not alone. Suddenly the colours and music in the video shift from dark and bleak to brighter and more optimistic. The video then summarizes the findings of the COMFORT study, and ends with a page of evidence-based information and resources for women.

NAMING THE CAMPAIGN

We wanted the campaign name to resonate with our target audience and align with key themes from the video. We asked women living with PVD for input on the campaign name, and they emphasized it should capture women's fundamental point of tension and concern surrounding PVD, and that is this claim that since the pain is not visible on examination, then it's all in your head.

'It's Not in Your Head' seemed to be a very appropriate name for the campaign as this one statement captures the essence of the experience that women often face on their journey with chronic genital pain. We ran searches on social media to ensure the hashtag #ItsNotInYourHead was available. We found it wasn't associated with any particular condition, but it had been used by people discussing chronic pain, which validated our branding strategy.



Still taken from the #ItsNotInYourHead video.

REACH AWARD

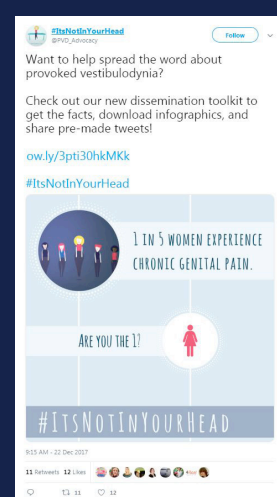
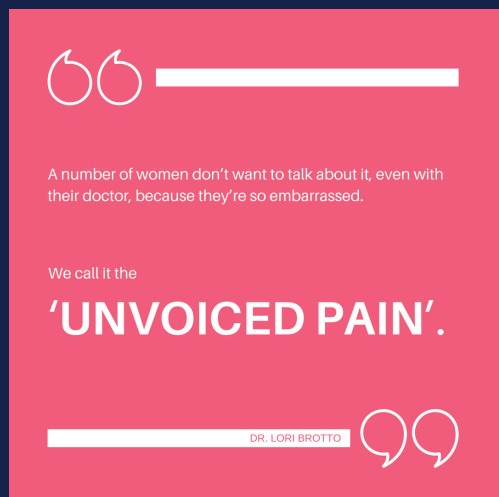
MICHAEL SMITH FOUNDATION FOR HEALTH RESEARCH

The MSFHR Reach Program provides a funding award of 10,000 dollars for teams of researchers and research users to support the dissemination and effective uptake of research evidence to inform and improve further research, practice and policy-making. We successfully obtained a REACH award with the proposal of disseminating the #ItsNotInYourHead video using a social media campaign.

DISSEMINATING THE VIDEO

Once the video was ready the next step was to develop a strategic plan for widespread dissemination to our target audience which is primarily women who experience chronic genital pain. The video was uploaded to YouTube, and officially launched as part of a social media campaign also called #ItsNotInYourHead.

The video, along with other relevant content were shared on the campaign social media channels, and the reach was tracked over a period of 6 months. Social media was strategically chosen as the primary mode of dissemination for the video as it has broad reach of audience, the public can access information on social media for free, and it presented an opportunity to provide social support to the population of women with PVD who are characterized as suffering in silence by starting a sensitive and empowering dialogue on a public platform.



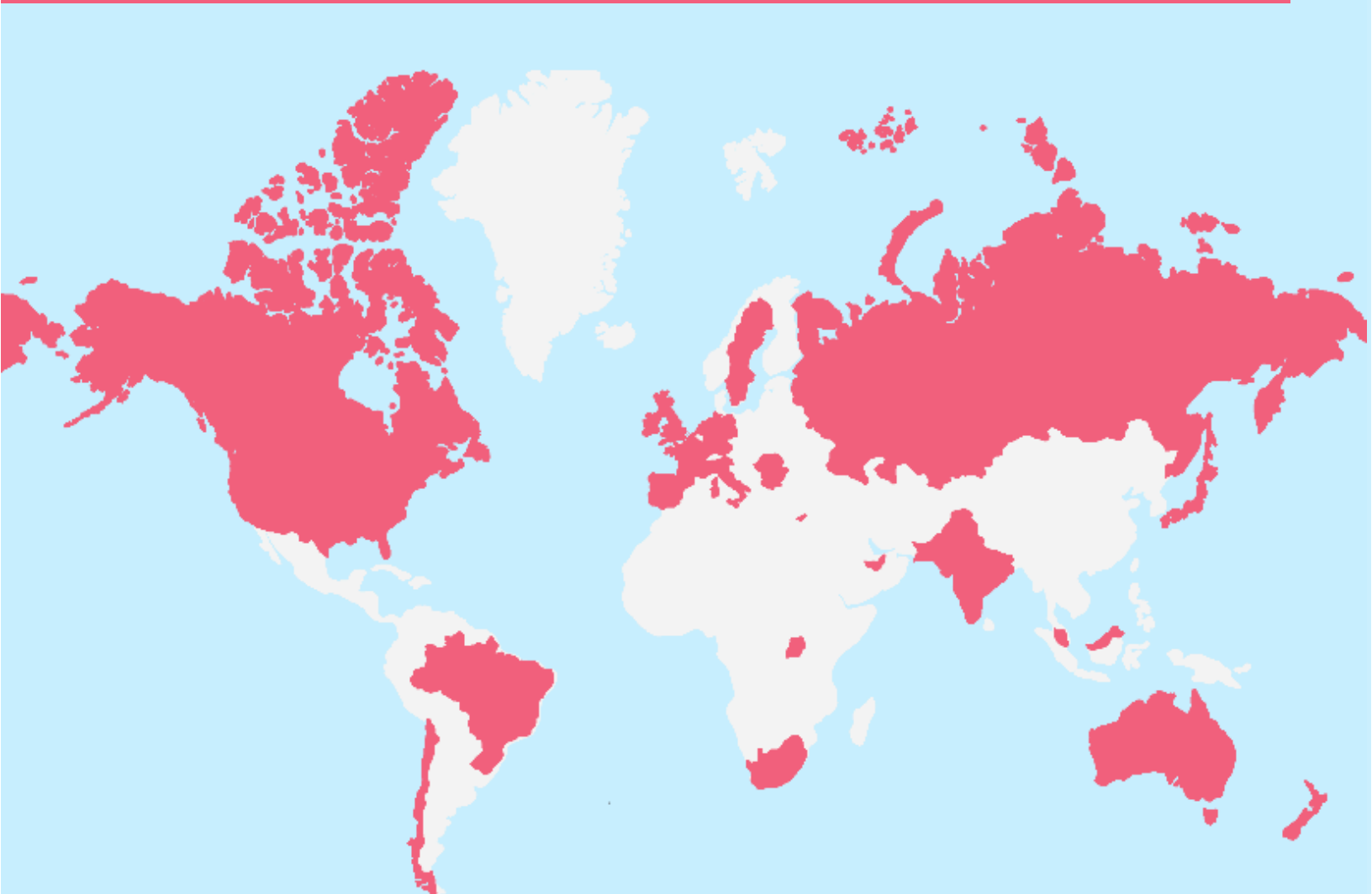
Screenshots of posts shared during the #ItsNotInYourHead campaign.

CAMPAIGN STRATEGIES

Throughout the campaign we used a number of strategies to increase engagement with our social channels and the content we promoted:

- 1 Created original content to promote the campaign messages using the script, GIF clips and stills from the #ItsNotInYourHead video
- 2 Shared online media which featured Professor Lori Brotto discussing PVD and Mindfulness to promote the science supporting the campaign messages.
- 3 Consulted a patient partner with lived experience of the condition on the campaign team who helped promote content, and gave a credible voice to the campaign.
- 4 Published 2-3 original tweets per week, 1 original Facebook post, and 1 Instagram post per week using the content management platform Hootsuite. We used images or graphics where possible to grab visual attention and boost post performance, and used Hootsuite to monitor our hashtag, keywords, and several key accounts so we could join in and amplify online dialogues related to our campaign messages.
- 5 Tapped into existing online communities that dealt with chronic pain, women's health issues, reproductive health issues, positive sex, and leveraged the support of women's health influencers, and relevant organizations with an established following of our target audiences.
- 6 Hosted chats on our Twitter account with various groups to demystify some of the common myths around PVD and shared evidence based information regarding treatment of PVD.
- 7 Wrote blog posts promoting the campaign and trial findings for various outlets we knew had a following of our target audiences.
- 8 Aligned promotion with trending and viral hashtags, awareness days, or 'take action weeks' (e.g. #FactFriday, #MindfulnessMondays, World Compassion Day, Sexual Health Week, International Women's Day, and National Pain Week).
- 9 Developed an easily downloadable and user friendly social media toolkit which included template posts, graphics, and guidelines on how and when to use them on social media platforms.
- 10 Retrieved weekly social metrics to analyze what content was performing well so we could strategically target future posts (for example, specific content that received high engagement, days and times of day with most engagements).

CAMPAIGN REACH



Afghanistan
Albania
Australia
Belgium
Belize
Bolivia
Brazil
British Virgin Islands
Bulgaria
Canada
Cayman Islands
Chile

Colombia
Costa Rica
Curacao
Cyprus
Denmark
Djibouti
France
Germany
Ghana
Greece
Grenada
Hong Kong

Hungary
India
Ireland
Isle of Man
Israel
Italy
Japan
Kazakhstan
Liberia
Malaysia
Mexico
Nepal

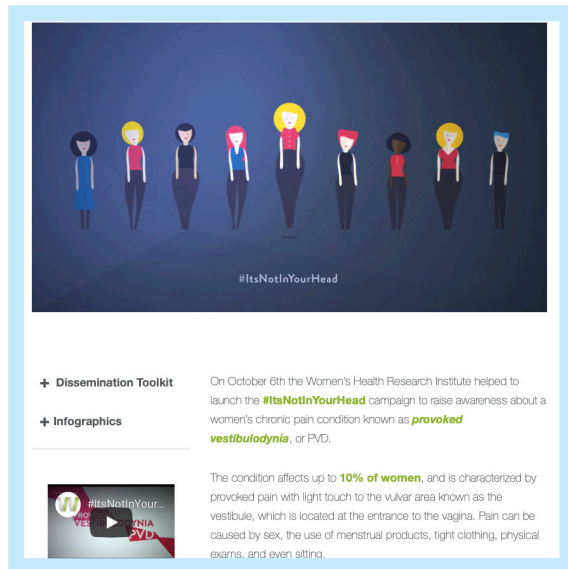
Netherlands
New Zealand
Nigeria
Norway
Pakistan
Portugal
Romania
Singapore
South Africa
South Korea
Spain
Sweden

Switzerland
Thailand
Trinidad and Tobago
Turkey
Uganda
United Kingdom
United Arab Emirates
United States of America
Vietnam

Pink areas denote countries the campaign reached, across our various social channels.

SOCIAL ACCOUNTS

Breakdown of the #ItsNotInYourHead campaign reach by social accounts:



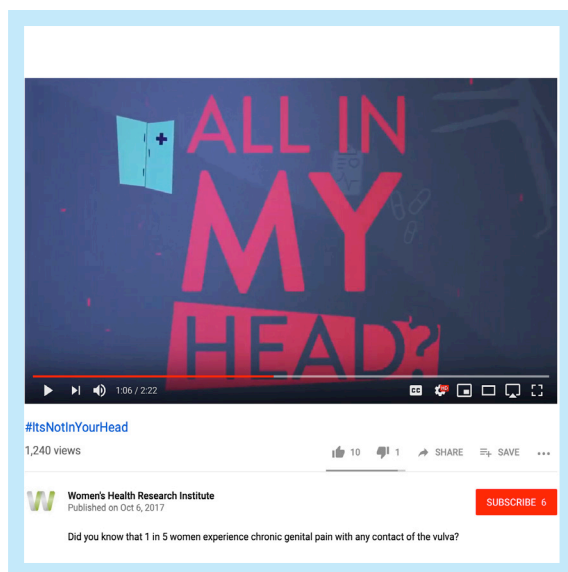
WEB

whri.org

We created a webpage dedicated to the campaign on the Women's Health Research Institute website. The page contained information about the campaign and how to get involved; the social media toolkit; links to the campaign social media channel handles; and the embedded #ItsNotInYourHead video.

Unique page views: 180

Average time spent on page: 1:59 minutes



YOUTUBE

www.youtube.com

The Women's Health Research Institute hosted the #ItsNotInYourHead video on its YouTube channel. We were able to track the unique reach of the video using the platform's built-in analytics.

Average view duration: 1:27 minutes

Views: 785

Likes: 9

Shares: 39

Countries viewed: 30

INSTAGRAM

[@PVD_Advocacy](#)

We gained approximately 40 followers in the short time our Instagram was active during the campaign period. Our posts often received more engagement than those on other platforms.

Impressions: 1077
Total likes: 253
Followers: 40

Campaign posts: 19
Impressions from hashtags: 97
Profile visits: 36

FACEBOOK

[@PVDadvocacy](#)

We used Facebook in two ways throughout the campaign. The first was a public-facing Facebook page, which, like our Twitter, promoted our video and useful information about PVD. The second was a private Facebook group, which gave women with PVD a space to discuss the condition and build a community for support.

Followers: 53
Page likes: 48
Highest reach on a single post: 198

TWITTER

[@PVD_Advocacy](#)

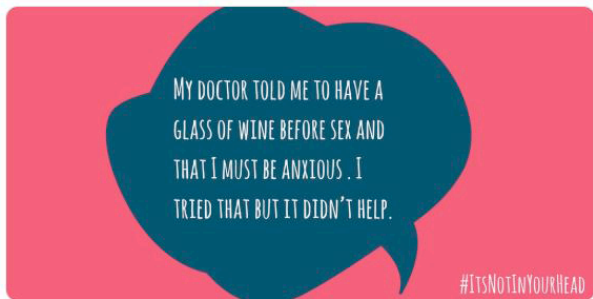
Twitter is a microblogging site. Since its inception in 2006, it has become a site for politicians, celebrities, and academics to actively communicate with the general public.

We chose to use Twitter to disseminate our video and to try to connect with women who might have had PVD.

Impressions: 108029
Engagements: 2307
Retweets: 402
Replies: 42
Likes: 414

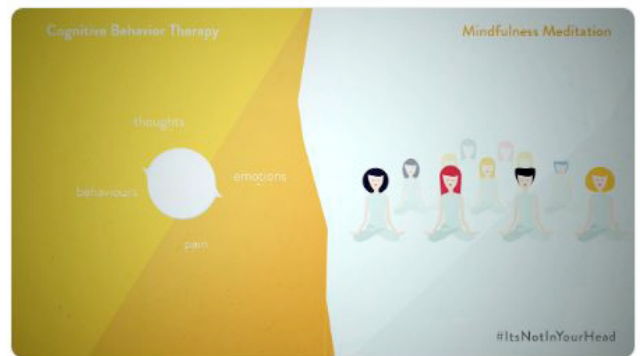
URL clicks: 341
Hashtag clicks: 134
Media views: 1047
Media engagements: 314

This is not a solution! We need to help raise awareness about [#PVD](#) not only so that people know the symptoms, but also so that healthcare professionals are equipped with the knowledge to diagnose and treat it.
[#ItsNotInYourHead](#)



10:35 AM - 16 Feb 2018

Looking for a way to manage pain associated with provoked vestibulodynia ([#PVD](#))? [#Mindfulness](#) therapy is an evidence-based treatment option, and it may be your answer!



9:05 AM - 10 Mar 2018



pvd_advocacy • Follow

pvd_advocacy We're hosting a Twitter chat! Do you have questions about [#provokedvestibulodynia](#)? Bring those questions, and bring your friends this Friday at 10am PST, where we will be joined by our patient partner and UBC Sexual Health Lab! --
 --
[#womenshealth](#) [#vulvodynia](#) [#gynaecology](#) [#sexualhealth](#) [#srh2018](#) [#chronicpain](#)
 artworks.gallery Great feed!
 pvd_advocacy @artworks.gallery thanks! ♡



18 likes

FEBRUARY 14, 2018

Did you know up to 10% of women are affected by provoked vestibulodynia?
[#PainAwarenessWeek](#) [#ItsNotInyourHead](#)



9:07 AM - 8 Nov 2017

Have questions about [#PVD](#)? [@DrLoriBrotto](#) wrote for [@Globe_health](#) about the brain and [#vulvodynia](#). buff.ly/2xE6I3m
[#ItsNotInYourHead](#)



8:36 PM - 13 Oct 2017

SCIENCE-MEDIA PARTNERSHIP WITH EHM&CO

In addition to targeted dissemination via the #ItsNotInYourHead social media channels, we collaborated with the award-winning digital market agency Ehm&Co to further boost the campaign and its key messages to their Yummy Mummy Club (YMC) community. The partnership capitalized on the community's monthly reach of over 5 million people. They created an integrated program for the campaign, which ran from January 1, 2018 to March 31, 2018.

The program included:

- A custom article to share in the YMC newsletter and social media channels
- Promotional posts about PVD and the campaign on YMC social channels
- Twitter party
- Facebook Live
- Social Influencer Program

The logo for Ehm & Co, featuring the lowercase letters 'ehm' in a bold, sans-serif font, followed by '&co' in a smaller, similar font, all in white on a dark circular background.

TOTAL REACH OF YMC PROGRAM

20.9M

IMPRESSIONS

61

POSTS CREATED

9.5K

ENGAGEMENT



ERICA EHM, FOUNDER AND CEO OF EHM&CO

YMC CUSTOM ARTICLE

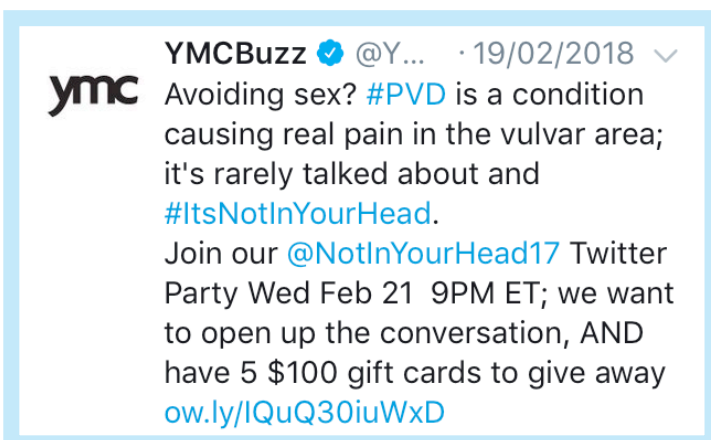
A custom article about Provoked Vestibulodynia and the campaign was featured on YMC.ca to engage and educate our audience about PVD, and encourage our community to participate in the conversation and receive the support they deserve. The article was also included in the monthly YMC newsletter.



EXCERPT

If you have symptoms of PVD (painful to touch; uncomfortable sex with no other explanation), the most important and reassuring thing we can tell you is that it is NOT in your head. This pain is real. You should know that people who care about pain – scientifically-recognized-white-lab-coats-kind-of-people – are working hard to do something about it. Women are amazing (look at us; we're freakin' awesome!) and we should feel empowered in our self-care. There are proven treatments for PVD, including evidence-based psychological treatments; measures which have been proven effective in the management of PVD symptoms.

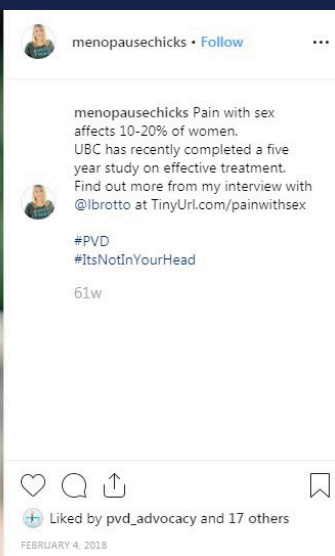
Page views: 1942
Average time spent on page:
3:24 minutes
Engagement: 1161



SOCIAL POSTS

YMC created custom social posts to live on their social channels to help amplify the #ItsNotInYourHead campaign.

Total posts: 29
Potential social impressions: 368,115
Engagement: 185



FACEBOOK LIVE

YMC hosted a Facebook Live with guest Dr. Lori Brotto, Executive Director of the Women's Health Research Institute and Principle Investigator on the COMFORT Study, who spoke about PVD.

Views: 30,900
Engagement: 66



SOCIAL INFLUENCER PROGRAM

Five social influencers in the YMC network were enacted to support #ItsNotInYourHead, using key messaging and imagery. Influencers created a variety of engaging content that was showcased on their social media platforms, including Pinterest, a platform that the #ItsNotInYourHead channels had not extended to.

Posts: 30
Potential Social Impressions: 1.5 million
Engagement 3,184





#ItsNotInYourHead

HOW TO TAKE PART IN THE #ITSNOTINYOURHEAD TWITTER PARTY:

1. Follow **@YMCBuzz** on Twitter.
2. Join us on Twitter on **Wednesday, February 21** at 9pm ET / 6PM PT.
3. Watch for tweets from **@YMCBuzz** and tweet your answers to the questions using the hashtag **#ItsNotInYourHead** for your chance to win. The Twitter chat lasts only one hour, so follow @YMCBuzz closely.

Good Luck!

TWITTER PARTY

YMC hosted a Twitter party to increase engagement, awareness, and reach for the #ItsNotInYourHead campaign. Harnessing Twitter to connect and communicate with an audience on the topic of PVD and women's chronic genital pain was one of the campaign's most successful dissemination strategies.

During the one hour chat, 101 individuals participated, and generated a total of 3400 tweets about PVD, other chronic genital pain conditions, and the importance of self-advocacy when seeking a diagnosis or treatment for these conditions. The chat was among the top 5 trending Twitter hashtags in Canada!

Participants: 101

Potential social impressions: 19,049,942

Engagement: 4,873



Erica Ehm ✓
@EricaEhm

You know social media is awesome when a twitter party about vulva pain is trending across Canada. Talk about powerful knowledge translation!
[#ItsNotInYourHead](#)

21/02/2018, 18:45

Q: WHAT IS A TWITTER PARTY?

A Twitter party is a sponsored live chat using the Twitter platform and hashtag (#) search feature to connect participants to an ultra-fast paced conversation stream on a specific topic.

Individuals are incentivized to join the party to discuss a topic of interest, and the opportunity to win a sponsored prize. It is a useful tactic for quickly boosting your profile, growing your reach, and engaging in dialogue with your current followers as well as new followers.

Twitter Parties - What is A Twitter Party. (n.d.). Retrieved from <https://www.5minutesfrommom.com/twitterparty/>



CAMPAIGN LEARNINGS FROM YMC

This campaign really resonated with our community in a very special way. Although we may not have had an overflow of comments, we know (through views of the article and Facebook Live, and participation in our Twitter Party), that this was a topic that people wanted and needed to learn more about. The opportunity to be a vessel for this information was so important to us!

The two strongest tactics for educating audiences were the Twitter Party and the Facebook Live. Being able to reach a significant number of people in short amounts of time allowed for the educational portion of this campaign to be successful.

The YMC article was another key tactic in this campaign, and, based on the higher than average page views, was an important learning tool for our YMC audience.



CAMPAIGN REFLECTIONS

WHY THE CAMPAIGN WAS A SUCCESS

Dedicated Campaign Team: The campaign team consisted of a group of dedicated individuals who were extremely passionate about the #ItsNotInYourHead cause and message, and also had an extensive skill set which lent itself to the successful management of the campaign. In order to grow a following on social media many hours are needed to create, source, and schedule relevant and meaningful content for your audience, so having team members with protected time to contribute to the campaign was essential.

Patient Partner: Having a dedicated patient advocate as a member of the campaign team was a key ingredient to the campaign's success. Having the unique experiences of living with PVD, receiving treatment, as well as using the web and social media to research the condition pre-diagnosis meant we had the lens of our main target audience guiding us throughout the campaign. The patient voice in campaign activities truly added value in engaging women online and getting the information across in an accessible and relatable way.

Partnership with YMC: Partnering with a digital marketing agency meant the campaign was amplified in a much more rapid manner and received extensive online exposure to a variety of audiences and outlets that may not have been reached through our own efforts. YMC's editorial teams used their expertise in storytelling to translate the scientific findings in an engaging and accessible way that resonated with a broad audience. This partnership also meant we added new online marketing tactics to our social media tool box.

“ I HAD NO IDEA THAT SO MANY
OTHER WOMEN EXPERIENCED
EXACTLY WHAT I DO. ”

IMPACT OF CAMPAIGN

The #ItsNotInYourHead campaign had two major impacts 1) raising awareness about Provoked Vestibulodynia and new evidence of effective treatment options and 2) initiating a dialogue about genital pain, vulvar health, and the stigma that often surrounds these issues. Starting this conversation, and sharing this information on social media resulted in women all over Canada, and further afield coming forward to speak up and break the silence surrounding genital pain and women's sexual health issues. The #ItsNotInYourHead messages and the voices of women were widely shared and heard.

WHAT'S HAPPENING NOW?

One year on from the targeted social media campaign the #ItsNotInYourHead social channels continue to grow and share information about PVD and the effective treatment options with the public. It has become an internationally recognized resource known for providing evidence-based information, empowerment, and support. It has also started to fill a gap in the lack of online resources for this population.

While audiences may now have increased knowledge of PVD and of the work being done to enhance the care of women living with this condition, we now need to determine what impact #ItsNotInYourHead is having offline in terms of the numbers of women seeking the psychological therapy treatment options, and if the time it takes women to receive a diagnosis of PVD has lessened. Dr. Lori Brotto and her team are doing further research to mobilize this evidence and expand the offering of #ItsNotInYourHead.

CAMPAIGN TEAM

DR. LORI A. BROTT



Dr. Lori Brotto is a Professor in the Department of Obstetrics and Gynecology and the University of British Columbia, the Executive Director of the Women's Health Research Institute, a Canada Research Chair in Women's Sexual Health, and a Registered Psychologist. Her research program of 15 years involves the development and evaluation of psychological interventions for women experiencing sexual difficulties and/or genital pain. Her role on the campaign was to provide leadership, overall strategic input, and mentorship to the team. She was also the face and host of Campaign Outreach activities including the Twitter chat with YMC Buzz and Facebook Live.

LANA BARRY



Lana works for the Chronic Conditions Self-Management Program at the University of Victoria and promotes health and wellness locally. After developing Provoked Vestibulodynia she became a women's sexual health advocate. She is sharing her personal journey to stop the silence and let others know that 'it is not all in our heads'. She has a MEd from UBC and has recently been a co-lead investigator of a study related to this topic. In addition to her professional expertise, Lana was a study participant in our CIHR-funded study evaluating psychological treatments for women with chronic genital pain, and she was a team member in our end-of-grant knowledge translation work in developing the infographic video. Lana brings a rich combination of professional expertise working with individuals living with chronic conditions, and her own personal experience as a patient, to this role.

CIANA MAHER



Ciana is a Digital Health Research Program Manager at the Women's Health Research Institute with an interest in Knowledge Translation and sharing evidence-based health information with the public. Ciana has a keen interest in social media as a medium to start conversations and raise awareness about health issues, especially those that are silenced and stigmatized.

MELISSA NELSON



Melissa is the Communications Assistant at WHRI, where she assists with management of the Institute's social media, creates web-based content, and helped run the #ItsNotInYourHead campaign. Melissa has a keen interest in social media and its potential as a tool for social change, and enjoys seeking new ways to leverage these platforms to foster dialogue about important issues.



GLOSSARY OF SOCIAL TERMS

Impressions: Times a user is served a post in their timeline or search results

Engagements: Total number of times a user interacted with a social post. This may include sharing, liking, commenting, or clicking somewhere on the post (e.g., a link or to play a video).

Retweets: Tweets which were re-shared by another user

Replies: Times a user replied to our content

Likes: Times a user liked our content

Hashtag clicks: Clicks on hashtag(s) used in a post

Link clicks: Clicks on a URL



#ItsNotInYourHead was funded by a Michael Smith Foundation for Health Research Reach Award, which provides funding to support the dissemination and uptake of research evidence to inform and improve further research, practice, and policy-making.

How to cite this report:

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