

Prostate Cancer Foundation Canada Support Services: A Quick Guide

Support services for support group leaders, their groups, and their members + how to access them - all in one place

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Background and Purpose

Prostate Cancer Foundation Canada ("the Foundation" - formerly Prostate Cancer Foundation BC) has been providing leadership and resources in prostate cancer support, awareness, and research for over 25 years. The Foundation was started by a small group of prostate cancer support group leaders and advocates, and grew over the years to include a network of approximately 20 prostate cancer support groups in BC.

In 2020, the Foundation expanded its support services to assist support groups, patients, and their loved ones outside of BC as well, and began to operate their expanded support services arm as 'Prostate Cancer Support Canada.'

Joining into the Prostate Cancer Support Canada network gave support groups across the country an opportunity to be part of a community of support groups again, including:

- Listing their group on the national support group directory
- The opportunity to share their meetings on the nationwide support group calendar
- Free meeting insurance for groups that were not their own registered charity/non-profit
- A national brand/identity including logos and marketing materials
- Invitations to support group workshops and conferences
- And the help of dedicated employees to assist with support services

There have never been any costs or requirements for support groups to join the network, and benefit from any of the services that we offer.

The primary goal of this document is to ensure that everyone who is in a leadership role for a support group in our network is aware of all of the services that we offer, and that they may access.

Becoming Prostate Cancer Foundation Canada: "The Name Change"

At the end of August 2023, Prostate Cancer Foundation BC changed its name to Prostate Cancer Foundation Canada to reflect our commitment to continuing to provide grassroots, equitable support to anyone affected by prostate cancer, no matter where in Canada they live.

More background on the name change can be found in the official press release.

'What does the name change mean for support groups?'

It's important to note that despite our name and logo changing, the Foundation remains the same grassroots organisation; the services that we provide will not be affected.

The following document was sent to all of the Canadian support group leaders on August 25th, 2023. It goes through what support groups and leaders need to know regarding the transition: What does the PCFC name change mean for me and my support group?

We kindly ask that if you have not already reviewed this document, that you do so, to understand how the name change may impact your support group, as an important part of our support network.

Services for Support Groups and Their Leaders: What We Provide

Above all - we want you to feel like you're part of a community!

After the amalgamation of Prostate Cancer Canada with the Canadian Cancer Society, we heard from many support groups that they were feeling like they were left without a home. Since then, we've worked hard to try to ensure that all of the Canadian prostate cancer support groups feel like they're part of a community that they can depend on.

Working with leaders across the country, we've also tried to determine the best *tangible* benefits for the support groups in our network, and have come to offer all of the following resources to all groups who are interested.

Advertising

- → Logo and branding
- → Support group directory
- → Support group calendar
- → Marketing materials
- → Free, local newspaper advertising
- → Support group newsletter

Logo and Branding

Any prostate cancer support group in Canada who wishes to take advantage of our services may request a Prostate Cancer Support logo customised to their group.



Please note that while your group may go by another name for example, 'Prostate Cancer Support Group X City' or
'Prostate Cancer Support and Awareness Group X City' - we
kindly ask that we keep the individual logos consistent using the naming convention 'Prostate
Cancer Support X City.'

For more information about logos and brand colours, please click here.

Reach out to support@prostatecanada.ca if you need a logo, or require a different file format for your logo.

Support Group Directory

Our Support Group directory includes over 70 groups and support contact points across Canada. It may be found on the Prostate Cancer Foundation Canada website under the 'Get Support' tab under the menu item, "Find a Group.' <u>Click here to see the directory.</u>

Listings may include your group's:

- → Province
- → City
- → Name



- → Contact information for up to 4 leaders or group contacts, including:
 - Name
 - ◆ Email address
 - Phone number
 - Title i.e. leader, steering committee member, rural contact, etc.
- → Website
- → Meeting information:
 - Date
 - ◆ Time
 - ◆ Location
- → Notes i.e. any other details that do not fit into the above categories



ALL I NATIONWIDE I ALBERTA I BRITISH COLUMBIA I MANITOBA I NEW BRUNSWICK I NEWFOUNDLAND & LABRADOR I NOVA SCOTIA I ONTARIO I PEI I QUEBEC I SASKATCHEWAN

We kindly ask that leaders help us keep this directory up to date by letting us know of any changes to their group's information, as soon as possible.

Please reach out to support@prostatecanada.ca to request changes.

Support Group Calendar

The support group calendar is a shared resource for support groups across Canada that may be utilised for sharing their support group meetings, speakers, and events.

The purpose of this calendar is twofold:

- to make it easier for support groups to get the information about their meetings out in the world
- to help patients more easily find local or virtual meetings, and speakers of interest



PCFC staff is happy to help you input your meetings, as needed. Or, you may use the following guide to upload your meetings on your own.

Marketing Materials

Prostate Cancer Foundation Canada's Support Services provide **complimentary design and customization of marketing materials** for support groups in our network. Coverage for printing and material costs differs, depending on the group's needs.

A catalogue of available support group marketing materials is available here.

This link includes:

- → Information on our funding model for materials
- → How to get your materials printed
- → An order form
- → Examples of each material

Materials available via this guide include:

- → Support group advertising:
 - Rack cards
 - Meeting posters
 - Business cards
 - Retractable banners
 - Sandwich board meeting signs
 - ◆ Tri-fold brochures
 - ◆ Flyers
- → Awareness and education:
 - About Prostate Cancer poster
 - Get Checked postcard
 - ◆ Should I Get Checked? Postcard
 - ♦ It's Time to Have the Talk with Dad brochure
 - Prostate Cancer and You brochure
- → Digital materials:
 - Websites
 - Powerpoint templates
 - ◆ Email signatures

If there is a material your group needs, but is not listed in the above catalogue, we may be able to help. Please see <u>the catalogue</u>, then reach out for more information.

Once you have decided on which materials you would like, <u>use this survey</u> to get your order in to us. We will reach out if we have further questions, and confirm the order details with you.

Local Newspaper Advertising

A new offering! If your support group is needing help getting the word out, we can help you submit a request to have your support group meetings included as a community event in your local newspaper. Most local newspapers offer this service free of charge.

If you want to take advantage of this offering, please reach out with your location and/or local newspapers you wish to advertise in. We'll get back to you with the criteria to post your meeting (word count, info required, inclusion deadline, etc.) and are happy to continue submitting these community requests, so long as you submit them to us every month.

Reach out to meyer@prostatecanada.ca for more information.

Monthly Support Group Newsletter

The monthly Support Group Newsletter, known as 'Your Monthly Debrief' is released on, or around, the 3rd Monday of each month and includes information on upcoming support group meetings, webinars, and community events, as well as updates on research opportunities, clinical trials, educational seminars, and much more.

Your Monthly Debrief is an opportunity for you to learn more about what's happening in your community. And given its distribution to a large audience of folks across Canada, it's also a great opportunity for you to share news about your group beyond your local community.

While we do not require support group leaders to share these newsletters out to their members, it is greatly appreciated when leaders do, as it helps to introduce their members to our organisation and how we may be able to also assist them on their journey.

Check out an archive of support group newsletters here and/or sign up for the mailing list.



Support for Meetings

- → Use of Zoom account
- → Hybrid meeting equipment
- → Meeting insurance
- → YouTube channel

Use of Support Group Zoom Account

The Foundation offers use of a shared 'pro' Zoom account to host your support group meetings. Free Zoom accounts have a meeting time limit of 40 minutes; a paid 'pro' account offers unlimited meeting duration for up to 100 participants, giving support groups the flexibility to have longer meetings without having to pay for their own account.

The only stipulations for use of the account are:

- That you be considerate when scheduling meetings and ensure that you don't double book the account/overlap with other meetings.
 - *Regularly scheduled support group meetings will always have priority over any other use of the account*
- That you ensure that you log out of the shared support group account before you join other Zoom meetings (in case another group is using it at that time and you accidentally boot them out)

We're happy to assist with setting up meetings for your group or to provide training to you, or any of your support group members, who require assistance with getting used to Zoom.

For more information, or to request use of our shared Zoom account, please reach out to support@prostatecanada.ca.

Hybrid Meeting Equipment

During the Pandemic, many support groups met online, and to accommodate the wide range of their members' comfort levels regarding in-person-meetings, many groups wanted to move towards offering hybrid (simultaneously in-person, and online) meetings.

Hybrid meetings provided the opportunity for members to make their decision on how to attend a meeting based on their health status, comfort level, distance from a meeting facility, and a variety of other factors.

For groups under the PCFC umbrella who wish to meet via 'hybrid' meetings: PCFC has been offering the necessary equipment, support, and guidance to get your group set up – at no cost to your support group.

All of the equipment that we are able to offer to support groups has been tested by PCFC support staff. Still, different meeting set-ups will require different gear and the patience of you and your leadership team working with us to determine an ideal plan for your group. We're happy to support you in any way that we can in setting up your hybrid meeting.

Want to take advantage of this offering?

- → Please see the information package for hybrid meetings here.
- → To order equipment, please fill out this survey.
- → If you have already obtained hybrid meeting equipment from PCFC, this video provides an overview/demonstration of how to use the equipment.

Meeting Insurance

When support groups reached out for assistance from us, one of their main concerns was how they were going to obtain meeting coverage. In response, the Foundation secured insurance for all Canadian support groups under our umbrella in 2021.

The insurance policy is renewed annually and covers:

- support group leaders and support group participants (excluding groups who are their own registered charities/non-profits)
- up to \$2,000,000 in commercial general liability
- legal defense costs and settlement costs against allegations for claims and lawsuits involving bodily injury and property damage
- up to \$2,000,000 in professional liability

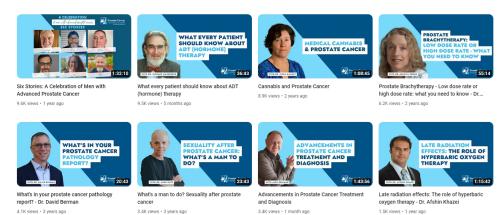
For more information about our insurance or how to obtain a COI (Certificate of Insurance), please see this document*. For all other questions regarding insurance that are not covered in the above document, please contact Leah Lariviere, Executive Director of PCFC, at leah@prostatecanada.ca

*Note that this document is from 2021, but the same coverage is offered now. The support group insurance policy is subject to change; support group leaders will be notified if their coverage is affected.



YouTube Channel

Our online video library features over 100 presentations by experts across the country. Videos are sorted by stage of disease, treatment type, and quality of life issues.



Some examples of topics that are covered in the video library:

- Side effect management including incontinence, sexual and erectile difficulty/dysfunction, depressions and anxiety, etc.
- The latest in prostate cancer research including current research on advanced PCa drugs, personalised medicine, and more
- Nurse navigators, urologists, and radiologists answering patients' most asked questions
- Information on theranostics and PSMA PET scanning and treatment

These videos may serve a couple of purposes for you as a support group leader:

- they're a great resource for groups struggling to secure speakers who may wish to share these videos at meetings to start a discussion
- they're also a great resource for patients hoping to learn more about a specific topic from a trusted expert; you may wish to refer your members to a video to learn more when you don't have the answer yourself

Please check out the video library here.

Or subscribe to our YouTube channel here: https://www.youtube.com/@ProstateCanada

Support for Leaders

- → Support Group Handbook
- → Assistance with finding speakers
- → Assistance with finding meeting venues
- → Fundraising opportunities/fund-sharing agreement
- → One-on-One support

Support Group Handbook & Leadership Training

This manual is intended to help guide users through the establishment of a Prostate Cancer Support Group.

While the branding and available services in this document were last updated in 2022, the information and guidelines in this document remain a helpful resource for:

- Onboarding new support group leaders to existing groups
- Existing support group leaders who would like to refresh their knowledge/review
- Folks starting a new support group

View the Support Group Handbook here.

Assistance with Finding Speakers

If you wish to host a presentation about a specific topic at an upcoming support group meeting, and need assistance finding the appropriate speaker, please let us know and we will try our best to help.

Securing speakers can sometimes be difficult. If we can't help you get someone to speak to your group, we will help you find an alternate video or resource to share at your meeting.

Assistance with Finding Meeting Venues

If you are in need of a new meeting venue in your local area, we're happy to help.

Please let us know your requirements (approximate vicinity that's preferred, locations that are a definite 'no,' if you have a budget for your rental, whether you require a location with A/V equipment or if you already have access to equipment, etc.) and we'll do our best to find you a suitable location to host your meetings. We will reach out to venues on your behalf, negotiate rates, review insurance

requirements, and anything else that needs to be done to help you find the best location for your group.

Assistance with Vetting Scientific/Research Studies

Quite often, we receive requests from research companies and the scientific community to share their surveys, clinical trials, and other research opportunities with our patient community. We are careful to ensure that the studies that we share with our community have gone through the proper ethics reviews and protocols necessary for them to be shared with our patient community.

Sometimes support group leaders aren't sure if the studies that have been share with them are legitimate and if they should be sending them out to their members. We are happy to review and vet any studies that are sent your way. Please forward them, and any questions, to support@prostatecanada.ca and we'll take a look.

Fundraising Opportunities + 50/50 Fund-Sharing Agreement

Support groups come in all shapes and sizes. Some larger groups are able to secure sponsorship and funding, while others are smaller and may have a very difficult time keeping afloat, paying for meeting venue rentals, and other support-related expenses.

PCFC offers a 50/50 fundraising agreement to try to help all of the support groups in our network with support group-related expenses.

For those who opt in, up to 50% of the funds raised by a Support Group 'team' during PCFC fundraisers, such as the annual Father's Day Walk/Run, may be eligible to be disbursed back to that group for reasonable expenses relating to their group.

For more information, please refer to this document.

One-on-One Peer Support

When you encounter a patient who is looking to hear from someone with very specific experiences that you're not sure you can assist with, or who isn't ready to participate in a support group setting, you may wish to refer them to the One-on-One program.

The One-on-One program pairs patients and/or their loved ones with volunteers from our prostate cancer community for a private, confidential chat. Supporters and supportees are paired based on the issues that they're experiencing, or specific treatments they're hoping to learn more about.

Peer supporters can help to point your support group member in the direction of helpful resources, then direct them back to your support group for continued support after providing them with the resources they need.

To set up a one-on-one chat for you, or another patient, please see our Peer Support - One on One page on prostatecanada.ca.

Note that PCFC is currently working on creating a **training program for prospective One-on-One volunteers** who wish to volunteer as peer supporters. The program will be online and provided in a work-at-your-own-pace format. No previous training is required, but we do ask that volunteers:

- Are at least 18 years or older
- Have lived experience of prostate cancer either as a patient or as a care-partner/support person
- Have good interpersonal skills particularly the ability to be patient, empathetic, and supportive
- Are comfortable with working with a diverse population

If volunteering for this program is of interest, please submit the supporter form here.

Support for Your Members

- → Free patient information packages Reef Knot Kits
- → Butts in Motion free fitness opportunities
- → If I Were Tom
- → Specialised support groups
 - ◆ Active Surveillance Support
 - ◆ Advanced Prostate Cancer Support
 - Partners in Prostate Support
 - ◆ Coast to Coast Prostate Cancer Support
 - ◆ GBTQ Prostate Cancer Support

Reef Knot Kits

Our Reef Knot Kit information packages are free to prostate cancer patients, their loved ones, and health care providers' offices anywhere in Canada.

Each Reef Knot Kit includes important resources to aid patients in understanding their diagnosis, making



difficult decisions surrounding their treatment options, and improving their quality of life with their cancer. We encourage anyone going through this journey to take the time to learn more about prostate cancer and take advantage of the resources provided in these kits.

These free information packages include (subject to supply):

- Your Prostate Cancer Passport a document that allows you to track important information, appointments, questions, and milestones on your journey
- Your Prostate Cancer Nutrition Guide
- Your Prostate Cancer Exercise Guide
- 2 full length books:
 - Prostate Cancer Strikes: Navigating the Storm by Gogs Gagnon a patient's journey through PCa

- Prostate Cancer: Understand the Disease and Its Treatment by Dr. Fred Saad and Dr.
 Michael McCormack an informational guide through the PCa journey
- Information on available support services
- Information on support groups
- A customised local support group flyer for groups that opt in
 - We will include a version of this flyer, customised to your group, to all kits that are ordered in your local area to help drive patients to your group
 - Please indicate if you wish to opt in to this program by clicking here

Reef Knot Kits may be requested by, and shipped free of charge in Canada to:

- Individual patients or their loved ones needing support
- Support groups who would like to distribute them at their meetings or in their community
- Doctors/urologists/oncologists who wish to distribute them at their clinics

For more information on PCFC's Reef Knot Kits, or to order one, please click here.

Butts in Motion

Butts in Motion is a free exercise and fitness initiative of Prostate Cancer Foundation Canada. Butts in Motion was created in 2021, piggybacking on the success of the Butts in a Boat dragon-boating team - the first prostate cancer patient-only dragon boating team in the world.

With growing research on the benefits of exercise for prostate cancer patients and the sustainability of programs that involve men with prostate cancer in a capacity where they are able to socialise and share support, evolving Butts in a Boat to widely encompass group fitness activities of all kinds for prostate cancer patients felt like a natural transition.

The Butts' mission is to help improve the survival, and quality of life, of men diagnosed with prostate cancer through fitness, support, and camaraderie.

Butts in Motion offers:

- → 2 Butts in a Boat dragon boating teams one in <u>Vancouver</u> and one in Moncton
- → Free, weekly online yoga classes
- → Free, twice a week online fitness sessions
- → Local walking clubs
- → And much more, including support to start your own Butts in Motion group

Butts in Motion is a great resource to be aware of, in the event that you encounter a patient looking for flexible, easy ways to get involved in prostate cancer-safe exercise and fitness activities. See the Butts in Motion site here.

If I Were Tom

If I Were Tom is a website that was created by PCFC (formerly PCFBC), in partnership with Dr. John Oliffe and his Men's Health Research team at the UBC School of Nursing and CIHR.

It offers an interactive way for patients to do their research on their prostate cancer diagnosis, build a plan, and stick to it.

Videos cover every part of the process from diagnosis to living well. After each video, resources and tips related to that part of your journey are made available to help you choose your next steps.

Check out ifiweretom.ca here.

Specialised Support Groups

Most local support groups offer support to patients at <u>all</u> stages of their cancer and often provide valuable insight about local resources.

In addition to referring patients to their local support groups, PCFC also operates 5 virtual, nationwide support groups to fill unique needs in the prostate cancer community, and create safe spaces for those needing them most.

Active Surveillance Support Group

Meeting online the 2nd Thursday of each month, the Active Surveillance Support Group offers support and information to patients interested in learning more about active surveillance, a non-invasive treatment option for low-risk prostate cancer patients.

The group is also open to patients and their loved ones who are already on the Active Surveillance journey and may wish to share their experiences with others or find support to navigate their journey.

If you have members interested in joining the Active Surveillance Support Group, please send them to this page to sign up: https://mailchi.mp/prostatecancersupport/active-surveillance-mailing-list

Advanced Prostate Cancer Support Group

Meeting online the 2nd Wednesday of each month, the *Advanced Prostate Cancer Support Group* offers support and information for patients and their loved ones, affected by a prostate cancer that:

- → Has spread (metastatic)
- → Is castrate-resistant or no longer responding to first-line ADT
- → High-risk or complex

The Advanced Prostate Cancer Support Group also has a confidential online forum where patients can reach out to each other 24/7 with their questions or share resources with each other. Check out the advancedprostatecancer.ca website here.

If you have members interested in joining the Advanced Prostate Cancer Support Group, please send them to this page to sign up: https://mailchi.mp/prostatecancersupport/advanced

Partners in Prostate Support Group

Meeting online the last Wednesday of each month, the *Partners in Prostate Support Group* is a safe place for partners, caregivers, spouses, and loved ones to come together and discuss the impacts of prostate cancer on their own lives in their roles as partners.

The Partners in Prostate Support Group also has a confidential online forum where patients can reach out to each other 24/7 with their questions or share resources with each other. Check out the partnersinprostate.ca website here.

If you have members interested in joining the Partners in Prostate Support Group, please send them to this page to sign up: https://mailchi.mp/prostatecancersupport/partnersinprostate

Coast to Coast Support Group

Meeting online the last Tuesday of each month, *Coast to Coast* is our general prostate cancer support group that features different expert speakers and topics, followed by discussion and a traditional support group meeting.

Coast to Coast meeting presentations are generally recorded and uploaded to our YouTube channel within 1-2 days following the presentation.

Coast to Coast meetings are always announced in <u>Your Monthly Debrief</u> and registration information may be found on the <u>Support Group Calendar</u>.

GBTQ Prostate Cancer Support Group

Meeting online on the 4th Wednesday of each month, the GBTQ group is a safe space for gay, bisexual, trans, queer, or MSM folks and their loved ones, who are affected by prostate cancer.

For more information about the GBTQ group, please visit <u>gbtqprostatecancersupport.ca</u>.

If you have a member in your group who is interested in joining the GBTQ group, please send them to the above website and have them submit a contact request to the GBTQ leader who will ensure that they are on the mailing list.

Opportunities

- → Support Group Councils
- → Conferences and Learning Opportunities
- → Research and Patient Advocacy Opportunities
- → Media and Awareness Opportunities

Support Group Councils: Your Opportunity to Get Involved

PCFC proudly works with 2 support group councils: the BC Support Group Council and the National Support Group Council.

The Support Group Councils function as separate committees within PCFC, operating as the primary linkage between the Foundation and prostate cancer support groups in the areas they cover.

Their mission is to assist and support prostate cancer support groups by providing guidance, resources, and networking leadership.

As a whole, Prostate Cancer Foundation Canada's Support Services and Support Group Councils aim to provide equitable prostate cancer support no matter where in Canada an individual may live.

The Support Group Councils provide support group leaders, and other advocates in the prostate cancer community, an opportunity to get involved with assisting other groups in their province and have a say in what's next for the Canadian prostate cancer support group community.

For more information:

- → See the National Support Group Council's guidelines* <a href=here.
- → See the BC Support Group Council's guidelines* here.
- → If you have questions, would like to volunteer, or would like to get in touch with your Council Chair or provincial rep/liaison, please contact support@prostatecanada.ca

*Please note that these guidelines have yet to be updated since our name change and still refer to PCFBC and PCSC, rather than PCFC.



Conferences and Learning Opportunities

The Foundation hosts Support Group Conferences approximately every 3 years. Pre-COVID, these Conferences took place in the Vancouver area and saw mostly support group leaders from BC, with a few joining from the rest of Canada.

During the Pandemic, PCFC hosted their first fully virtual Conferences in 2021 and 2022 and saw support group leaders and patients from around the world join in.

Our Conferences are often themed, and based on addressing the challenges facing our community of support group leaders at that time.

Our 2022 Conference included 2 days of presentations and experiences.

- → The first day focussed on 'The New Normal for Support Groups' and included a special presentation from Dr. Brian Goldman of the CBC Podcast, 'White Coat, Black Art,' as well as a virtual cocktail hour, Mix 'n Mingle providing support group leaders with an opportunity to get to know each other in a fun, informal setting.
- → The second day focussed on 'Prostate Cancer Realities' and featured research scientists and renowned doctors from across the country speaking on everything from mental health and anxiety, to online research, genetics, and your most asked questions about the most common side effects of PCa, surgery, and radiation.

We look forward to likely hosting our next conference in 2025. Please stay tuned for details and reach out if you wish to be involved with our planning committee.

The Foundation also hosts special workshops and forums for support group leaders from time to time.

The next forum will be held on October 28th, 2023, and has been organised by a group of support group leaders across the country to give all of the leaders in our community a chance to provide feedback on services, get to know each other, and learn from other groups.

Please click here to learn more and RSVP for the 2023 Leader Forum.

Research and Patient Advocacy Opportunities

From time to time, the Foundation is presented with opportunities from stakeholders in the prostate cancer community (other non-profits, research groups, pharmaceutical companies, etc.) to participate in research, patient advocacy panels, or focus groups.



When these opportunities are presented to us, we look through our roster of patients and support people to find the best fit for the position and will offer them to you.

Letting us know that you're interested in these opportunities, and giving us an idea of your demographics (age, treatment status, race, etc.), will help us to better understand your interest/eligibility for these roles.

Media and Awareness Opportunities

From time to time, the Foundation is presented with opportunities to be interviewed on the radio or local TV, by their local newspapers, or otherwise. We often present these opportunities to leaders in our community giving them a chance to raise awareness about their group, their journey with prostate cancer, and the work that they do in their community.

Other Things You Might Need to Know:

- → Prostate Cancer Foundation Canada website
- → Who's who at the Foundation:
 - ◆ BC Council members
 - National Council members
 - ♦ Board members
 - ◆ PCFC Staff
- → Events
- → <u>Volunteering opportunities</u>
- → <u>Donations</u> + <u>Other ways to give back</u>
- → Social media
 - Facebook
 - ◆ <u>Twitter</u>
 - Instagram
 - YouTube
 - ◆ LinkedIn
- → He's the Reason Patient Stories
- → Awareness Month Light Up in Blue, Awareness Website
- → Christmas campaign