

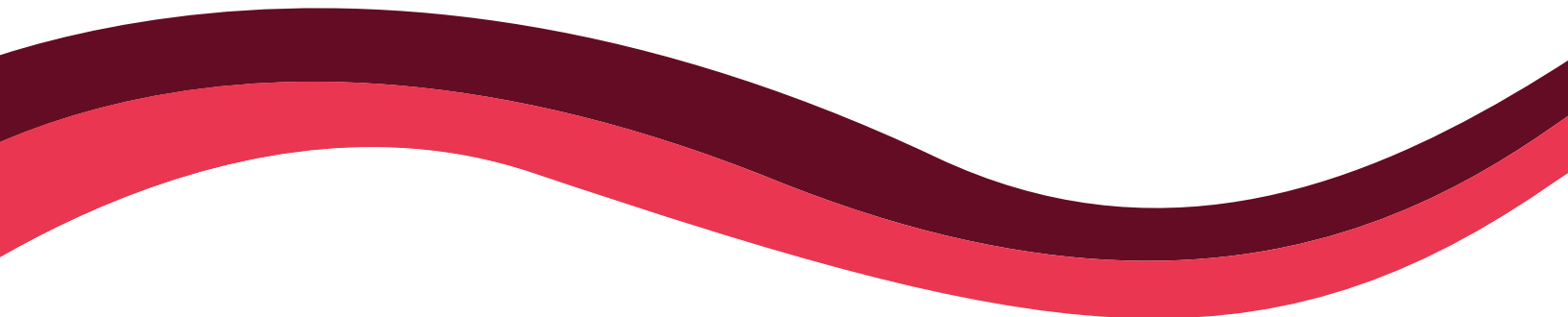
BDASC



RAISE YOUR SHIELD
BECAUSE WE ALL HAVE A HAND



2022 HEALTH EQUITY, DIVERSITY AND
INCLUSION INITIATIVE PROGRAM



2022-2023 Health Equity, Diversity, and Inclusion Initiative Project

Our work began with the ask!

The Invitation

A letter to the South Carolina Advocacy Coalition and Ambassadors, and community members

July 5, 2022

Dear Advocates,

We write to inquire about your interest in a new working group the Bleeding Disorders Association of South Carolina (BDASC) is establishing in partnership with its Advocacy Coalition to address bleeding disorders health equity in our state. It will be called the “Health Equity, Diversity, and Inclusion Initiative” (HEDI). Specifically, we plan to focus on examining disparities in health care access as they relate to specific groups, disease state specifics, regions of our state, and individual – family social economics. These specific groups included but are not limited to: African American and Latino communities; women with bleeding disorders; young adults and teens; people in rural areas; immigrants; ultra-rare bleeding disorders; Von Willebrand disease; our aging population; and those affected by physical disabilities and mental health challenges. It is imperative that we, as a community, address access to care and treatment barriers to all of our members, and this is an exciting opportunity to be the “boots on the ground” in this regard.

As a Subject Matter Expert (SME) member of the working group, you would be responsible for attending and actively participating in four meetings (many in-person, some virtual and all with a virtual option) in 2022-2023. The startup schedule for the group will involve the following:

- A meet-and-greet virtual Zoom Meeting on September 13th at 7:00pm, for introductions, general strategizing, and to establish the groups basic goals
- A formal virtual or in person meeting in the Chapter’s office on October 11th at 6:30pm to report out our progress goals and produce a report for the fall Advocacy Summit
- Present and report the group’s findings and 2023 goals at the fall Advocacy Summit, in Charleston, SC, October 21-23
- Early January 2023 in person meeting (During the beginning of the 2023 legislative session), and with a virtual option

We are proud to have received a grant from the National Hemophilia Foundation to address health equity in South Carolina and will be reporting our outcomes. We hope that you will favorably consider this invitation and we can count on your support.

You were selected from our Coalitions Ambassador and BDASC membership listing because of your own unique bleeding disorders expertise, community involvement and connections, and we felt you would be able to be a voice for the specific groups we are trying to raise awareness for. As you can see from the proposed schedule above, we plan to move quickly in getting this off the ground. You and your family will be invited to our exclusive 2022 South Carolina Health Equity Family Advocacy Summit the weekend of October 21-23, in Charleston at no cost to you or your family. Please do not hesitate to reach out to us by email or phone if you have any questions or prefer to discuss the details of this request. We look forward to working with you to help make quality health care access and education available for all people affected by bleeding disorders living in South Carolina.

Warmly yours in healthcare equity,

Sue Martin

Executive Director, BDASC, Advocacy Coalition Team Lead

864-350-9941

Sue.martin@bda-sc.org

Cristal Day, Advocacy Coalition Chair

864-770-3656

cristalday@yahoo.com

Following: The HEDI group met virtually on September 13th and again on October 11th as described above and the following summary report is a result of the two virtual meetings. We established a goal of trust and collaboration within the HEDI group which was necessary to have meaningful conversations. Excitement and gratitude for the commitment to health equity, diversity, and inclusion by the Chapter was stated by all HEDI members involved. Removing health disparities and barriers within access to care and treatment was the overarching goal of each member.

We wish to express our sincere gratitude and appreciation to the South Carolina Bleeding Disorders Advocacy Coalition and Ambassadors, each member of the HEDI Working Group, and the BDASC membership, for their time commitment, dedication, and involvement in this exciting project. We hope you enjoy reading this comprehensive report.



**The South Carolina
Hemophilia and
Bleeding Disorders
Advocacy Coalition**

The Coalition's Mission: To Empower the Hemophilia and Bleeding Disorders Community in South Carolina to speak to public and private decision-makers about improving Access to Quality and Affordable Health Care and Treatment.

REPORT FOR THE HEDI SUMMIT

Opening Summit Report

October 21-23, 2022

The following remarks were provided by Sue Martin, Executive Director and HEDI Project Lead at the opening night session of the HEDI Summit. These brief bullet points were shared with the attendees and were a direct result of the outreach and research of the two meetings with the HEDI Working Group. Each group member, (with some groups having more than one person) chose a different area of personal interest to address health disparities or access to care and treatment.

Engaging our teens in advocacy is important – Engagement is down nationally – they have a lot going on these days...

Continued teen programming will lead to better health outcomes in transitioning to adulthood for teen and young adults affected by bleeding disorders: They are also our Future Leaders. How do we get them to engage more?

Begin with camps for the kids- we do not have enough of our children attending camps for kids with Bleeding Disorders- WHY?

Current solution- Camp Burnt Gin is attending our Advocacy Camp for marketing the camps we currently have, having a session on Sunday with HTC's staff – encourage kids to want to attend- start them young!

Suggestions: Have a teen leadership for the board meetings of BDASC. They will do some programming, plan, etc.- Chair, Vice Chair, Secretary, resume building... continue having events they would like to have.

Mental Health Care is lacking in SC for individuals in need of mental wellness when dealing with the challenges of living with bleeding disorders- this is a huge area of need nationally and is being addressed, and is on our radar- what is the best solution that has a meaningful impact- the community needs to help us lead this discussion. Mental health needs for the stress of having to worry about affording the cost of care is a big concern.

Women with bleeding disorders must have treatment plans and be treated the same as men when it comes to their bleeding disorders. Carriers of bleeding disorders need to be viewed with a different lens in healthcare as not just carriers, but many times as women with bleeding disorders if they have symptoms due to lower clotting values, or symptoms even with normal levels- a huge area to raise awareness, voices, and conversations.

We discussed California's survey they did on women's bleeding disorders and decided to do one of our own and having it available at the HEDI conference. 85 women took the California survey with most saying they do not have a treatment plan or access to treatment when they bleed.

Solution: The survey link is ready now and we hope you will take it. Putting the invite out in our social media, e-newsletters, print, and on the evaluation at the end of the agenda. We encourage you all to take the survey and help us look at our women who bleed in SC.

Von Willebrand Disease needs to be treated with the same respect as hemophilia- this population would like to have a stronger voice in SC for quality treatment care, testing, healthcare facilities, and staff education. Access to what works for them and their needs, not just checking a box or putting them into a category and that is it- waiting for something to happen and then make a plan, is not the answer with the VWD population. A hysterectomy for women is not the solution if treatment less invasive is available but not identified yet due to being undiagnosed. Testing and treatment is complicated and it is not okay to just accept this and move on. They are often frustrated and stressed. Feeling validated, understood, and respected while heard, is a huge need. Much more education in the treatment care and diagnosis is needed; guidelines NHF and MASAC has provided is a good start, however better testing resources is needed. Here, individualized treatment is so important.

Solution: Already in motion- a community engagement opportunity just for the VWD community, a celebration of recognition for this population- to be held on November 18th in Columbia

Of Note: **In our membership** to date we have
73 families with women with VWD, 42 families with Men (some overlap with both)

Lower-income individuals and families, those on Medicaid, or without insurance, Medicare, disabilities, etc. need to be treated with respect and value when reaching out for help and treatment in the hospital system- DO NOT turn them away because of what you do not see in their need- a huge issue to explore and raise awareness. Pain control and medication is a need in the emergency rooms and those in pain from hemophilia bleeds are not “looking” for drugs, as often they feel they are being looked at with this lens.

Much discussion was around the inability to live on **disability assistance** one may receive and the inability to work and not go over that threshold, even if it is something you can now do to get out of the house, contribute, and work some. The need for the disability to cover your healthcare and factor is a need, but the desire to do more is the emotional and mental stress many still have. How can we get vocational training to help with job placement, resumes writing for jobs that those who qualify for disability can do, and with accommodations for the restrictions they have due to their disability.

The **minority populations** need to be involved and raise their voices and be engaged within the chapter- how do we get our minority community engaged and feel comfortable in sharing their challenges- something they are culturally not trained to do- (they keep challenges to themselves- and do not reach out)

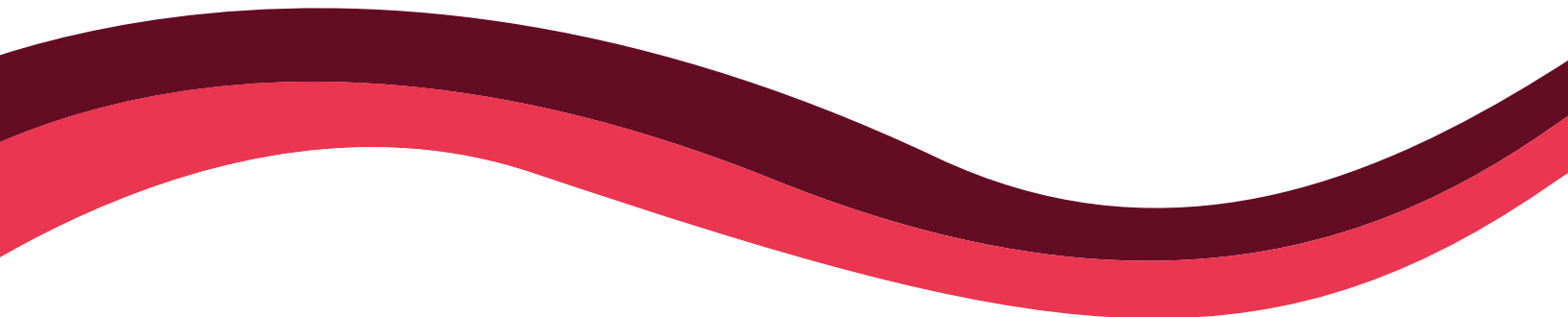
Solution: Continue to invite our minorities to serve on the board of directors, in leadership groups and committees, with the outcome possibility that others will see they are needed, welcomed, and included in all we do.



BDASC

Health Equity,
Diversity and Inclusion

HEDI Summit Work
October 21-23, 2022

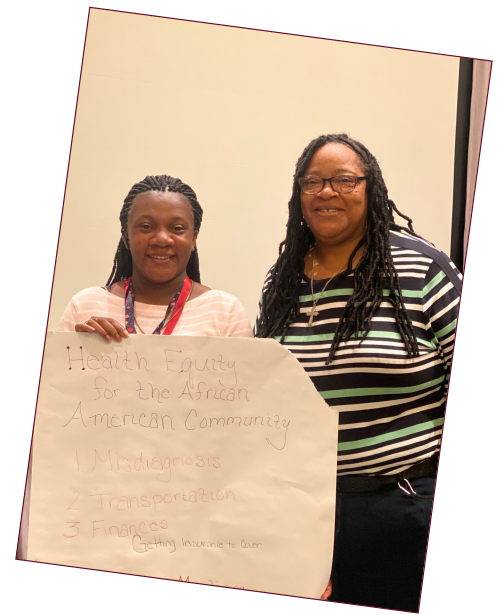
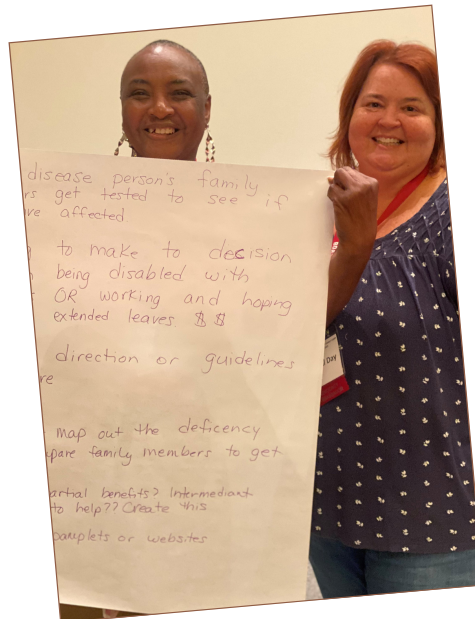
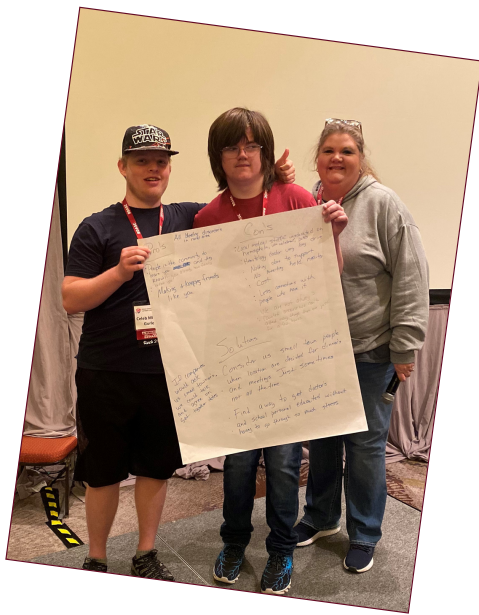




BDASC

Health Equity,
Diversity and Inclusion

About Our Work



Members of our community were asked to join in the conversation at our Health Equity Family Advocacy Summit. Members chose selected groups within the bleeding disorders community that have considerable barriers to care. These groups were to represent Low Income Families and those on Disability, or with Disabilities, Mental Health Needs, Rural Families, The African American and Latino Community, Women who Bleed, The Von Willebrand Community, Our Children, Teens and Young Adults, and The Rare Disorders Community.

Through a series of questions, Summit members came together to determine the most substantial issue(s) that their particular group faces. They wrote down their collective results and reported their comments. From there, with the community's help, we gathered information to derive attainable and actionable goals for our South Carolina bleeding disorders community.

HEDI REPORT FROM THE HEALTH EQUITY FAMILY ADVOCACY SUMMIT

Summit Group Activity Report

OCTOBER 23, 2022

What Did Our Health Equity Conference Discover and What Did Our Community Say?

The groups gathered again with community members in attendance to allow their voice to be part of the conversations. The groups listed below were what the attendees worked on and are listed in random order. They worked to provide the most important barriers and possible attainable solutions they had discovered as a group.

- Most barriers and solutions are listed in order of the group's importance (but not all).

Health Equity for Women with Bleeding Disorders

1) Updating educational programs to the most up-to-date Women's Bleeding Disorders Research (move away from the "50's")

- Getting HTC Reps into residency – newer conferences in MUSC, Columbia, Greenville
- Getting papers reviewing the newest research published and out to schools, hospitals, PCP, OBGYN's
- Design a Health Equity newsletter with research articles and personal stories
- Research information and personal stories (both)

2) Early testing for girls especially carriers and obligate carriers (daughters of fathers with hemophilia)

3) Moving away from hormone therapy as the first priority for women with bleeding disorders- concerns for future pregnancies, breast cancer, others

4) More research on Women with Bleeding Disorders

- How can women help to get more funding for research on women with bleeding disorders?

Health Equity for Individuals with Von Willebrand Disease

1) Getting more people tested – having the numbers can lead to more awareness / desire of companies to produce additional more stable tests, improve upon testing / products, more money = \$ more funding opportunities

2) Better testing and frequency of testing for proper diagnosis, consistency of protocols for testing, removing placing patients in a "box" when the treatment does not fit or work well

3) Education: Removing misinformation

- Prophy is possible and sometimes needed for VWD
- Making a VWD standalone page on the BDASC Website with updated information
- Getting Insurances to understand the benefits to patients for the use of Prophy

Health Equity for The African American Community

- 1) Misdiagnosis
 - More educational meetings
- 2) Transportation Needs
 - Pop-up clinics in areas such as Sumter, Darlington, Rock Hill
- 3) Finances
 - Getting insurances to cover treatment
- 4) Support Groups
 - Involve more outside members / Families and Friends, Pastors, Government Officials
 - Prayer can be useful in the groups (non-denominational)



Health Equity for Mental Health Within the Bleeding Disorder Community

- 1) For newly diagnosed patients and their families: Have a team of therapists, social workers, and other team members that can help with the struggles around the diagnosis, or with dealing with everyday situations; to include the whole family and siblings, esp. the youngest ones.
- 2) Offer free services for Mental Health - Having to be accessible- go to employers to ask for assistance.
 - How to get vocational rehab involved?
 - How to get programs to have the lower income individuals' voices heard?
- 3) Have an event with a therapist and the doctors to have them listen (a listening circle)
 - An incentive for docs or therapists, how can we make this happen (CEUs)

Health Equity for The Ultra Rare Bleeding Disorders Community

- 1) Testing for family members of a rare disease? Where did it come from?
 - Map out the deficiency and compare family members to get potential diagnosis of other family members
- 2) Need more education on treatment care and guidelines.
 - Resource pamphlets, books, or websites
- 3) Having to decide between being disabled with benefits or working and hoping for extended leaves. Hard to work with bleeds that last a long time.
 - Is there a way to get partial benefits? Intermittent disability to cover/ help? Can this be created?

Health Equity for Teens, Youth, and Children

- 1) Have the ER's knowledgeable of bleeding disorders and the diagnosis- continued education for caregivers too
- 2) Test babies early!
- 3) Increasing communication between children, teens, adults, schools, daycares, friends, churches
- 4) Get more teen engagement at camps, events:
 - Incentives- game trucks, gift cards, etc.

Health Equity for Bleeding Disorders in Rural Areas

- 1) Local medical staff and hospitals are uneducated on bleeding disorders
 - Educate the small-town doctors and school so the rural community members will have less stress in dealing with uneducated staff all the time alone.
- 2) Hematology doctors and HTC's are a long drive away
- 3) No local meeting to support the community in these areas
 - Small town events, just a few per year would be great.
- 4) The cost for travel can be troublesome and patients feel they have less connection to the community, feel they are not always counted because they cannot attend many meetings, events.
 - Would help to have friends and connections to the community.
 - Have patients be sure to attend virtual events for better connections to the community



In Conclusion, this opportunity for the community to have their voices heard, express their thoughts and possible solutions, work as a team with all members and staff of the Chapter, not only brought the members closer together but brought the organization into complete unity. The next steps will begin in 2023 as we tackle some of the areas that were brought to light by the HEDI Working Group and community members and take it step by step in closing the gaps of health disparities and barriers within health care access for the South Carolina Bleeding Disorders Community! Stay tuned...

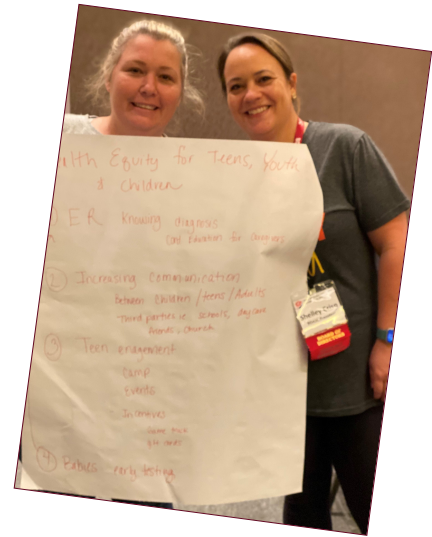
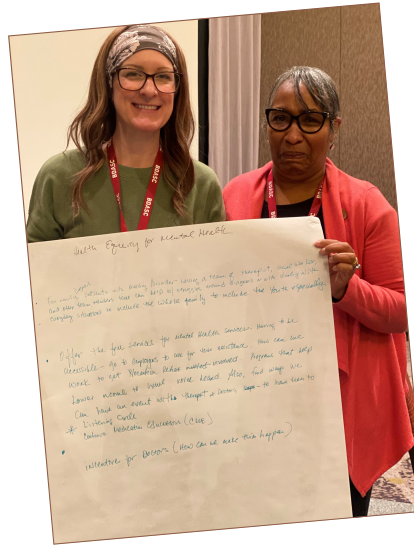
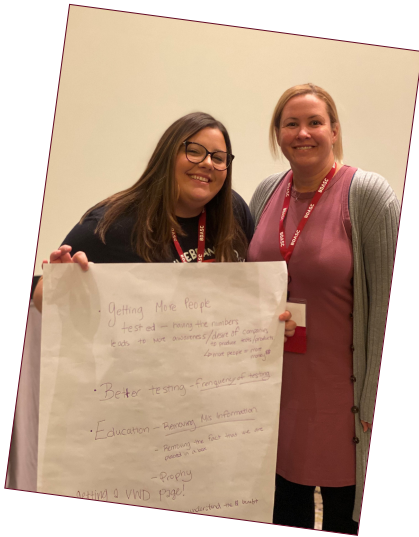
The following pages show additional steps in the process and the outcomes of our Bleeding Disorders Surveys; Women Who Bleed and the Evaluations of the entire Health Equity Summit Initiative.



BDASC

Health Equity,
Diversity and Inclusion

Our Progress



Within the HEDI Working Groups, Women who Bleed were defined as a group of undeserved people. As a means of addressing the disparities that women who bleed face, a survey was created to determine what their experiences have been. We provided the survey to any woman who was diagnosed with a bleeding disorder, who were in the process of getting diagnosed, or who believed that they should have a diagnosis.

This survey was divided into two parts: A Bleeding Assessment and a Treatment Survey. This survey was disseminated by putting the QR code and link on the Health Equity Family Advocacy Summit agenda, sent out via email newsletters, and various social media posts. The survey was open to any woman within South Carolina, although we have no control over who takes the survey.



Scan the QR code to review or
take the survey

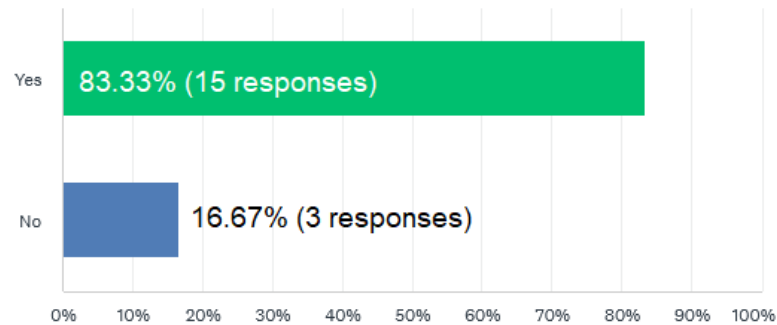
The Bleeding Assessment Survey had 14 questions
The Treatment Survey had 20 questions
Current results as of November 1, 2022



Women Who Bleed

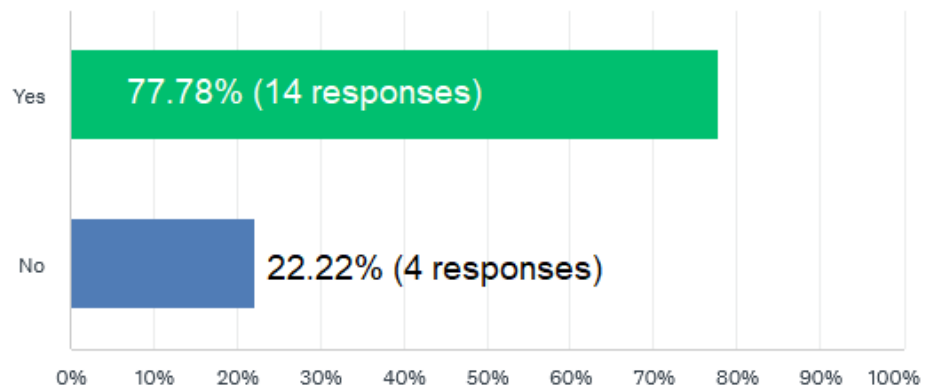
Do (or did) you frequently experience severe periods, characterized by excessive bleeding that may last a full week or longer (Excessive: bleeding through a tampon or pad in 2 hours or less)?

Answered: 18



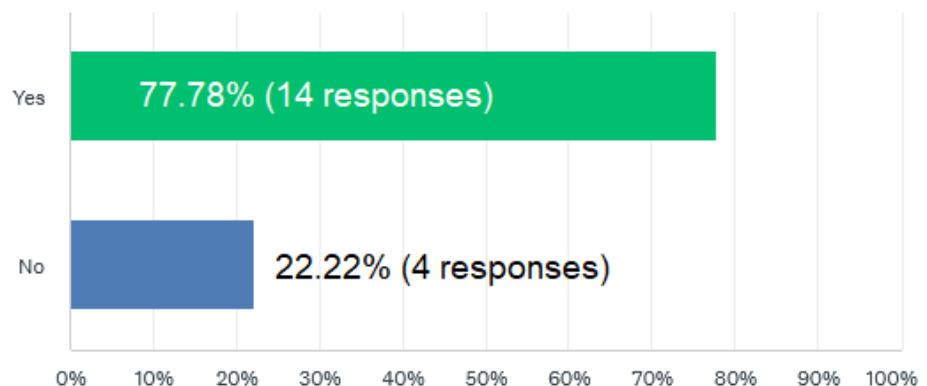
Have you ever been treated for anemia?

Answered: 18



Did you have your hemoglobin levels tested?

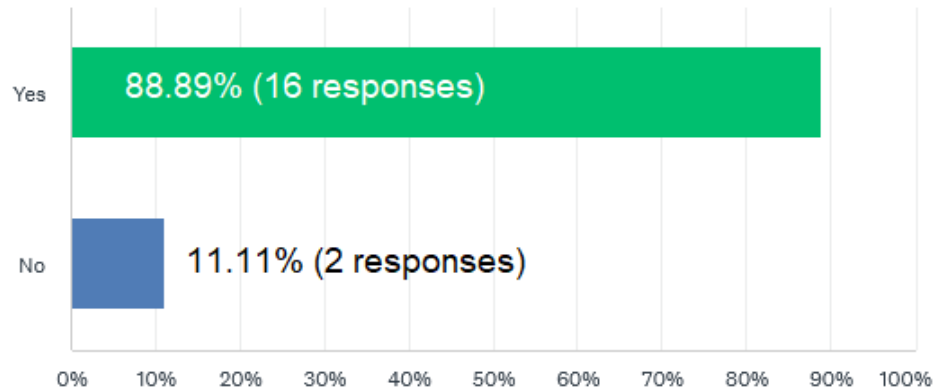
Answered: 18



Women Who Bleed

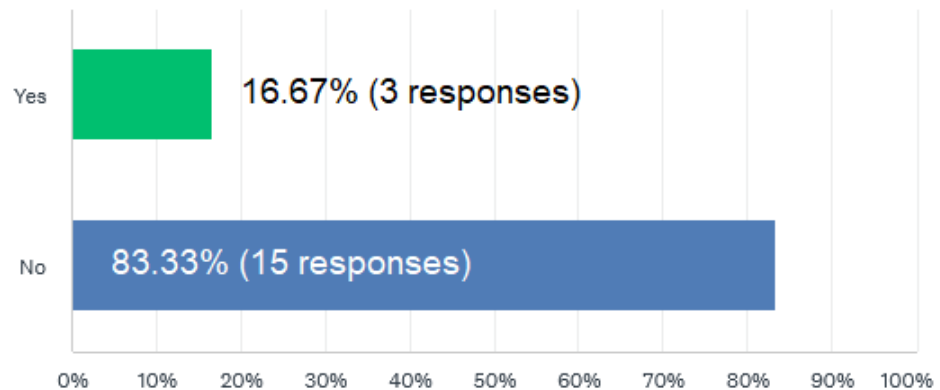
Do you bruise easily?

Answered: 18



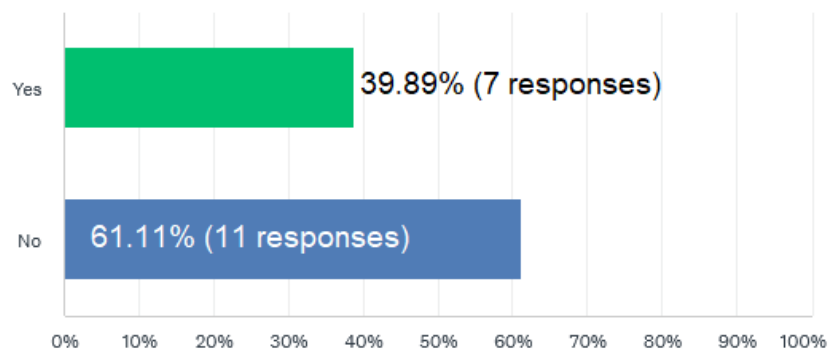
Do you have frequent nose bleeds?

Answered: 18



Have you ever had a problem bleeding after a tooth extraction or dental surgery?

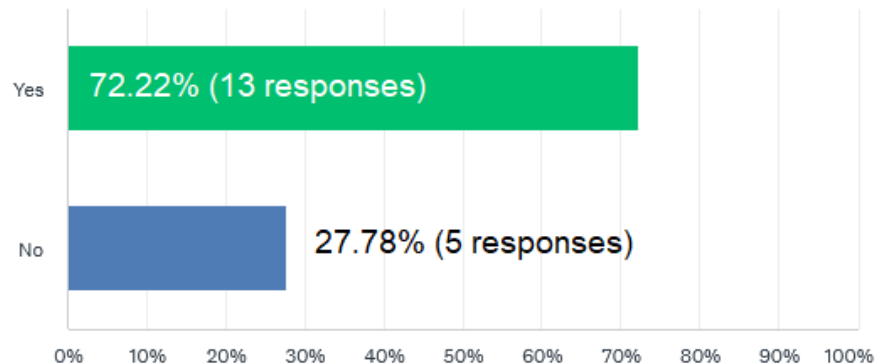
Answered: 18



Women Who Bleed

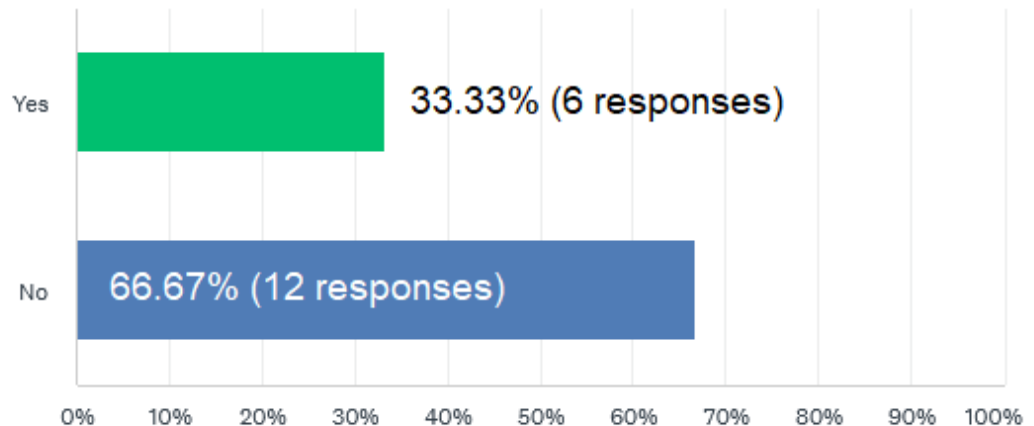
Have you experienced joint pain or stiffness not related to sports injury (for example, in your knees, ankles, or elbows)?

Answered: 18



Do you have arthritis?

Answered: 18

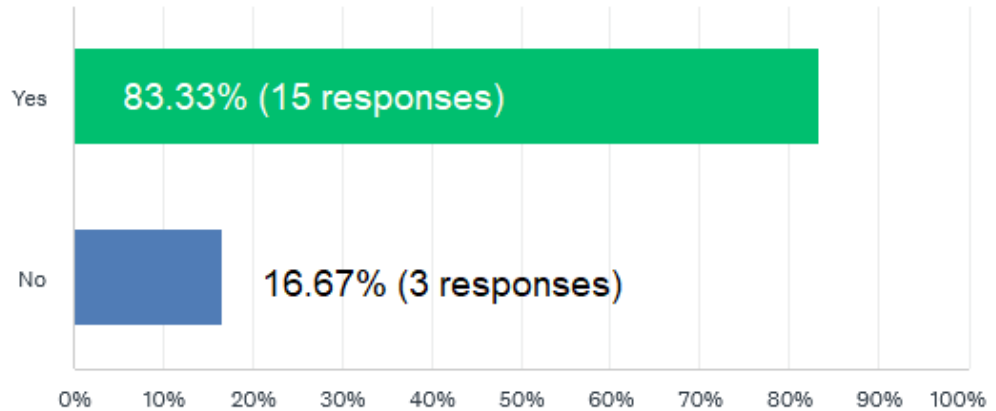


In reviewing this data, it appears that more information will be needed on this topic going forward. This being our first survey on this topic we did not collect demographics such as age. Additional survey's may be needed to target specific age related factors.

Women Who Bleed

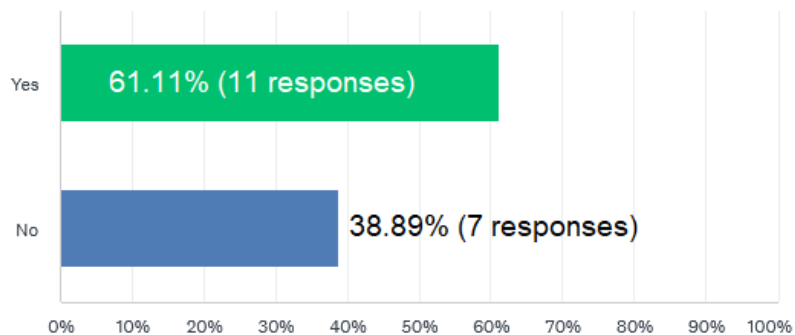
Have you ever given birth?

Answered: 18



Did you ever have bleeding problems following delivery or after miscarriage?

Answered: 18

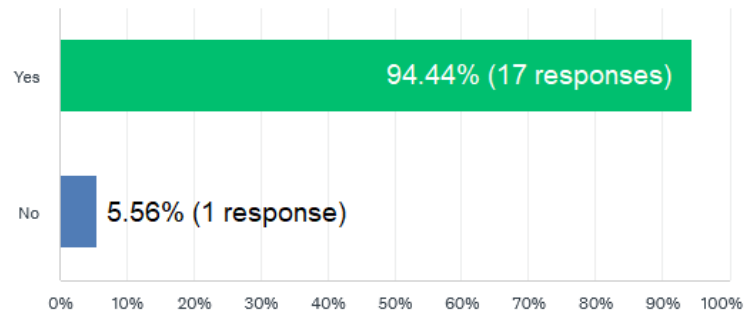


This survey focused on broad, high level questions to first capture the needs of our Women Who Bleed, and discover next steps. In reviewing the data related to miscarriage and delivery, it will be important to differentiate between the two to better understand the unique problems women face.

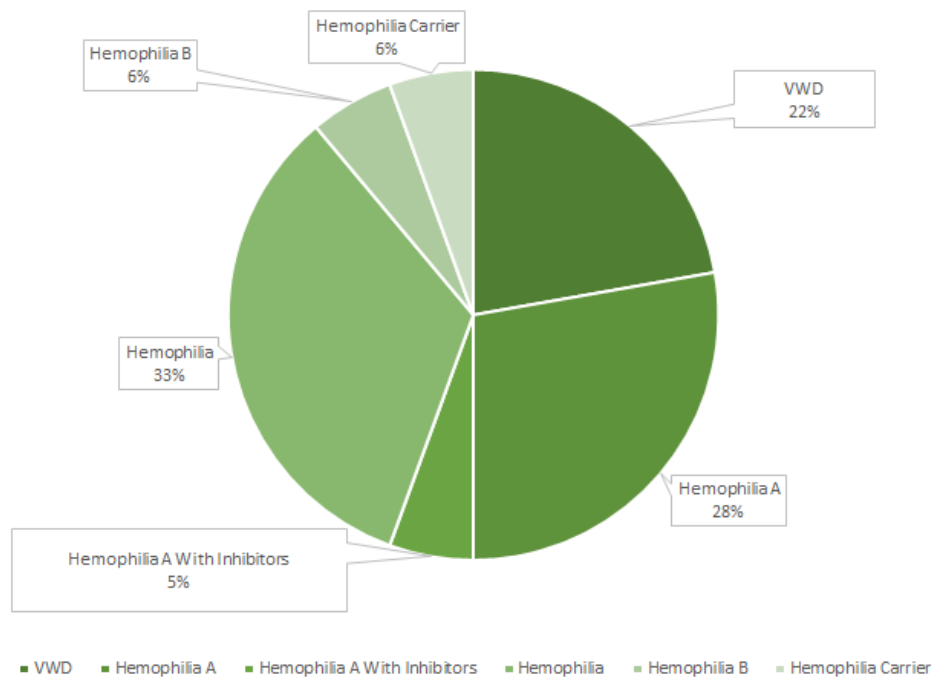
Women Who Bleed

Has anyone in your family been diagnosed with a bleeding disorder?

Answered: 18



Which bleeding disorder(s)?

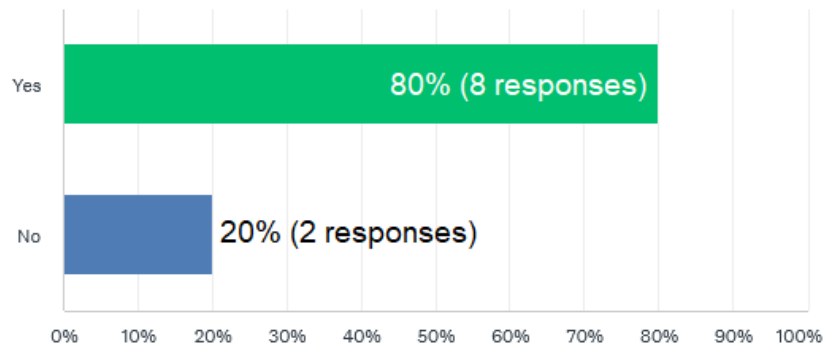


In an effort to account for multiple diagnosis and be inclusive to all diagnosis, the question "Which bleeding disorders [has anyone in your family been diagnosed with]?" was an open ended question allowing for multiple and varied responses. Respondents provided "Hemophilia" as an answer. In this scenario, we are unable to determine if this is because they are unaware of their type of Hemophilia, or that they just didn't put it. A similar situation occurred with VWD, although no respondents entered any type of VWD. Additional information will need to be gathered in future surveys.

Women Who Bleed

Have you ever sought treatment for yourself for a bleeding disorder or a bleeding related event?

Answered: 10

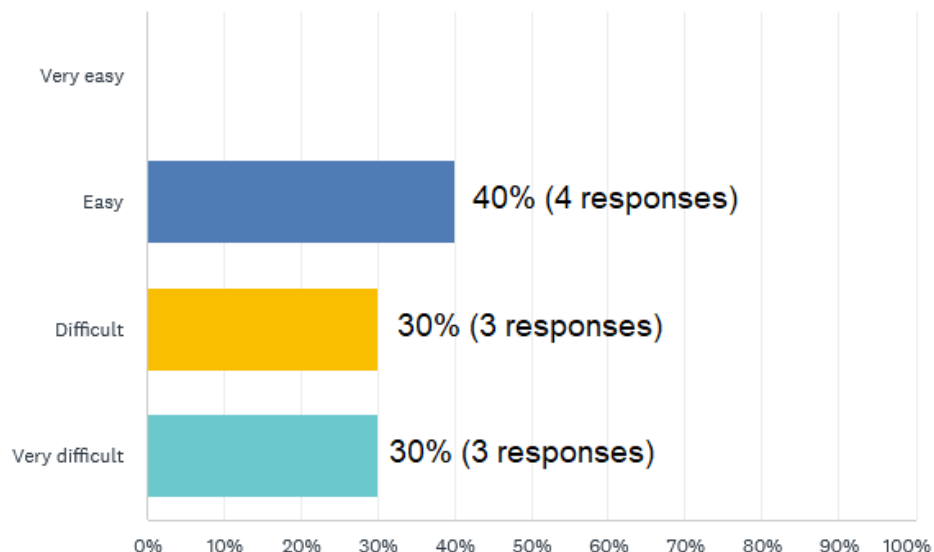


Respondent's reason for not seeking treatment:

"I wasn't diagnosed until my daughter was born and my symptoms are very mild."

How difficult was it to find a provider?

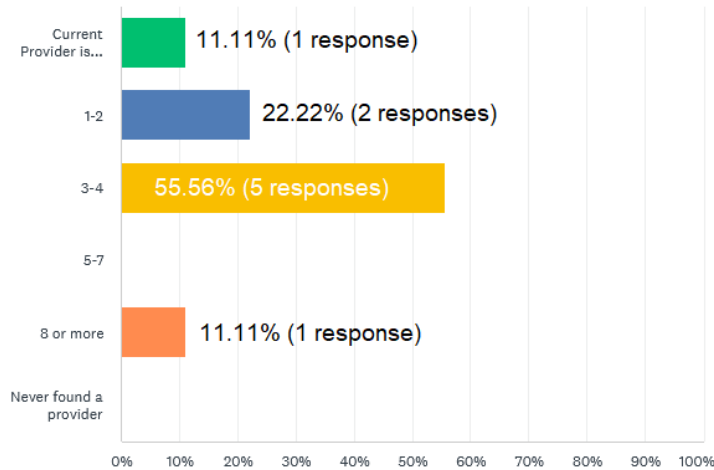
Answered: 10



Women Who Bleed

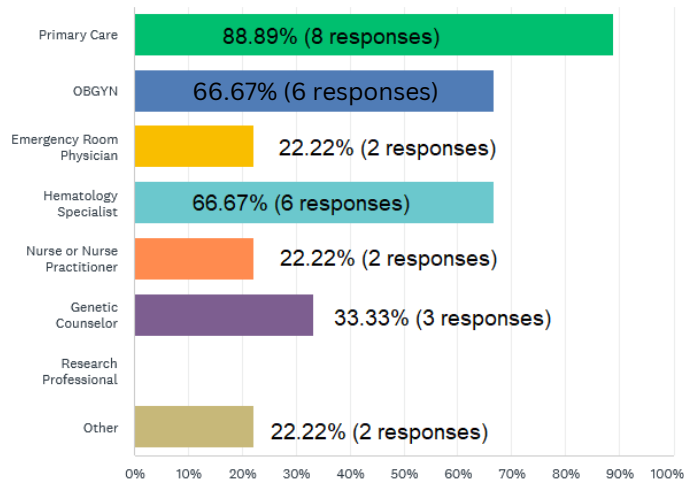
How many different professionals/medical providers did you visit before finding your current provider?

Answered: 9



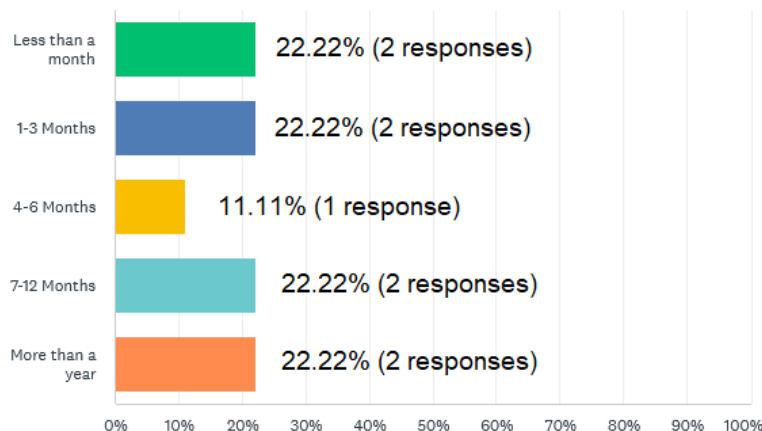
Which of the following professionals/ medical providers did you meet with when trying to find a hemophilia treatment provider? (choose all that apply)

Answered: 9



On average, how long did the process of finding a provider take?

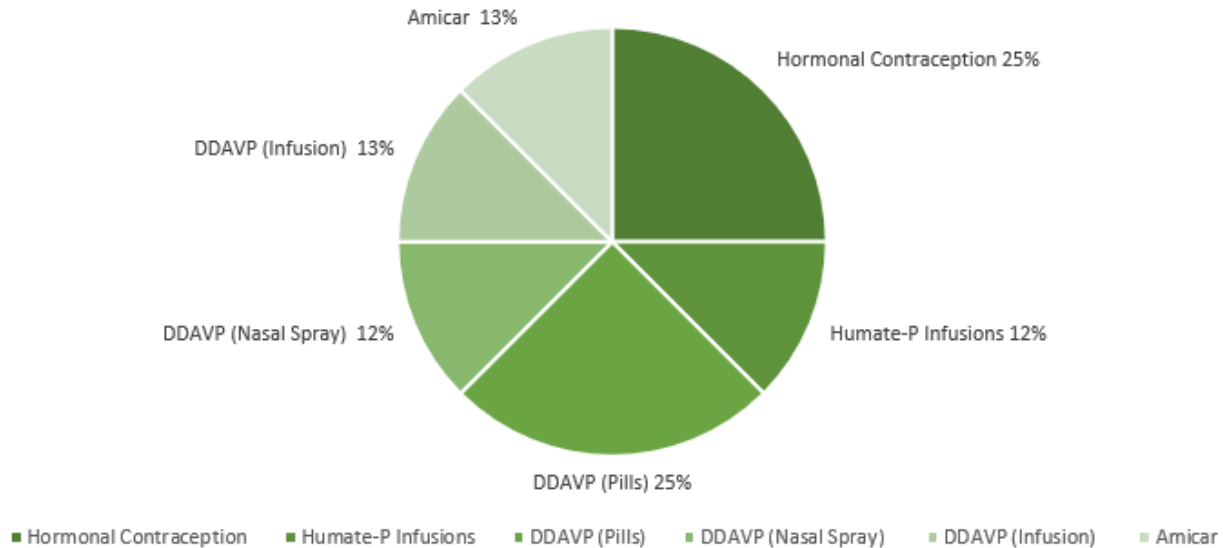
Answered: 9



Women Who Bleed

In the past, what types of treatment have you been prescribed or recommended for your bleeding disorder (include all- factor, pain medication, birth control, acupuncture, ect)?

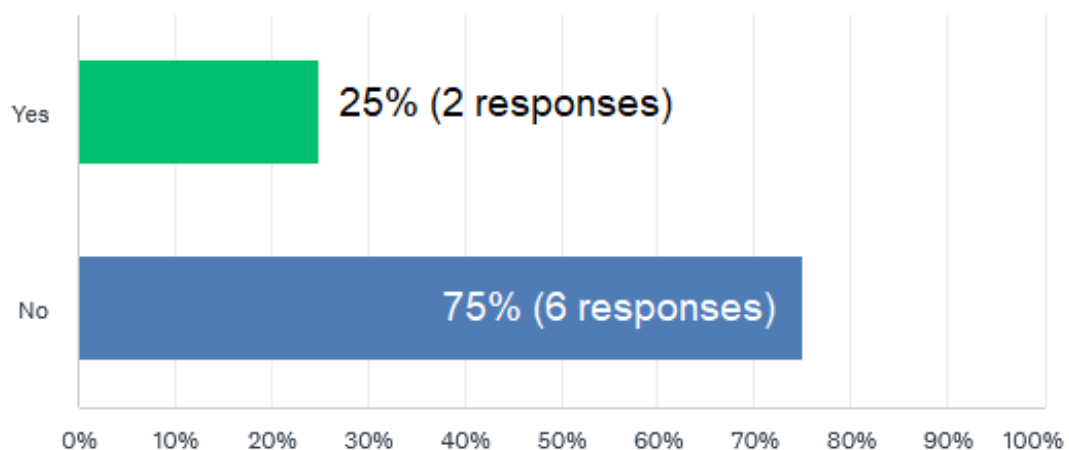
Answered: 8



In an effort to account for multiple treatments, as well as unknown treatments, this question was provided to respondents as an open ended question. Hormonal Contraception was used as a general term in displaying our results, but please note that specific hormonal contraception types were listed by the respondents.

Were these treatment recommendations helpful?

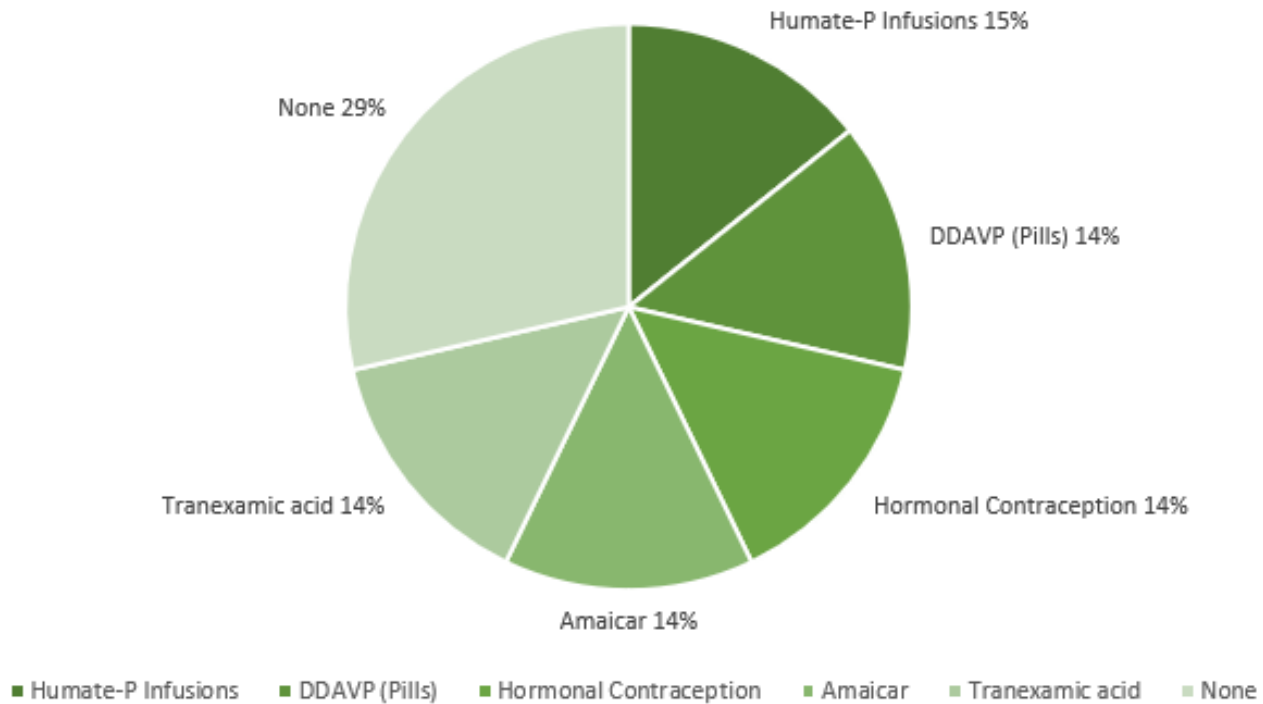
Answered: 8



Women Who Bleed

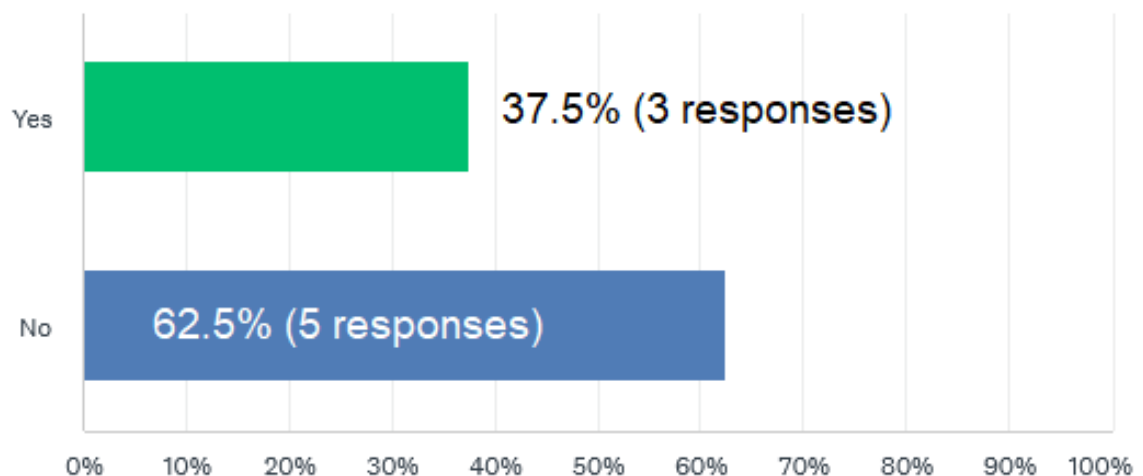
What treatment are you currently using to manage your bleeding disorder?

Answered: 8



Are you happy with this current treatment?

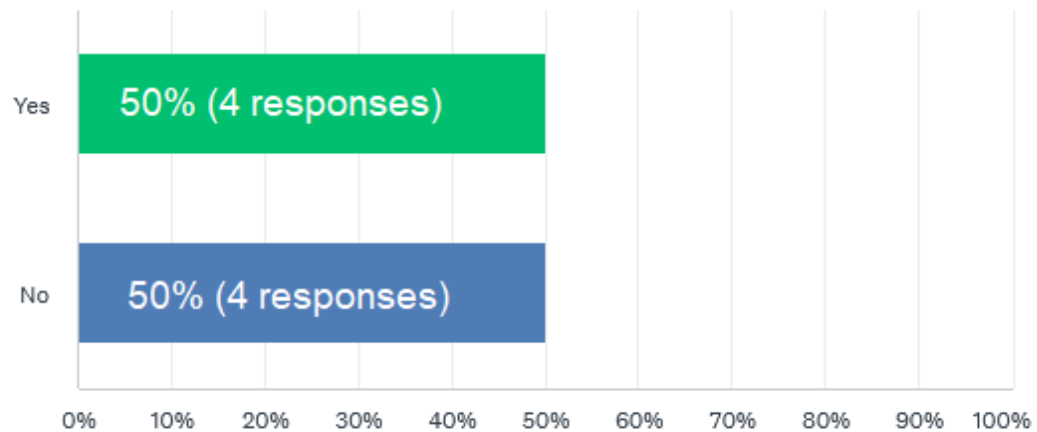
Answered: 8



Women Who Bleed

Are you treated at a HTC?

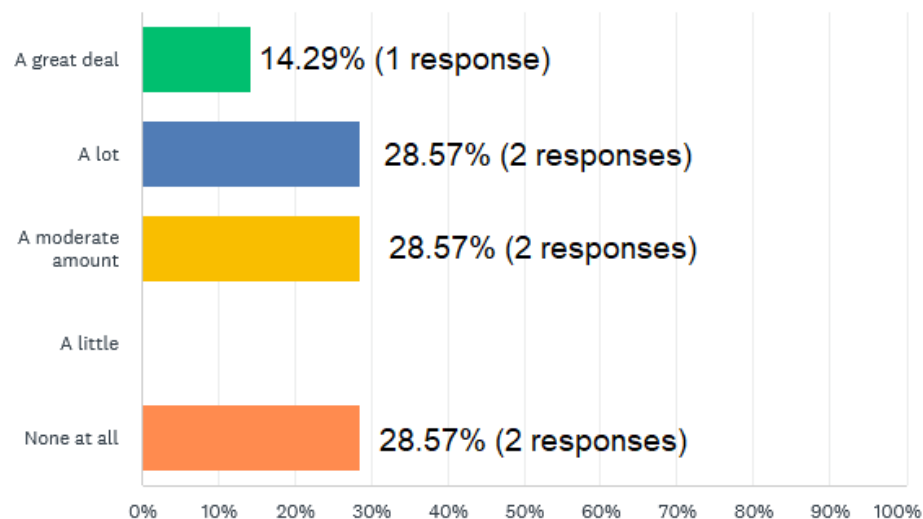
Answered: 8



Please note that HTC (Hemophilia Treatment Center) is a generally used term within the South Carolina Bleeding Disorder community as a means to describe seeing a hematology specialist in a clinic setting. We did not differentiate between a Federally Funded HTC (of which there are currently 2 in South Carolina) and a general clinic setting.

How well do you feel your provider understands your bleeding disorder?

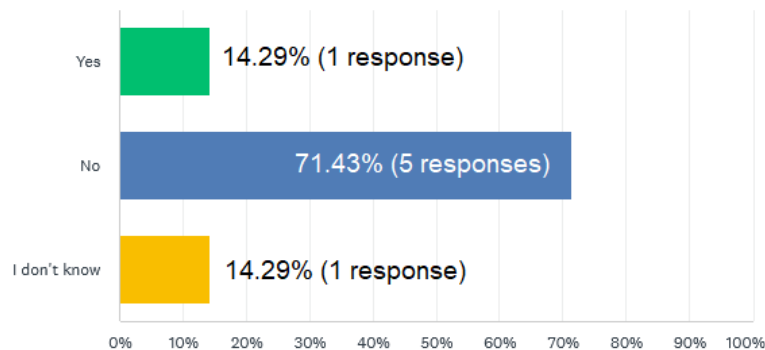
Answered: 7



Women Who Bleed

Do you think there are enough medical doctors in the area who treat women with bleeding disorders?

Answered: 7



Respondents were asked to answer the following questions in their own words. Their responses may have been modified for brevity and clarity. Not all respondents provided answers for the following 2 questions.

What resources did you use to find a provider (medical referral, google search, friend/family, NHF or BDASC type website, etc)?

- Medical referrals, NHF, BDASC, self advocacy
- My patient liaison set me up
- Google search
- Local Chapter

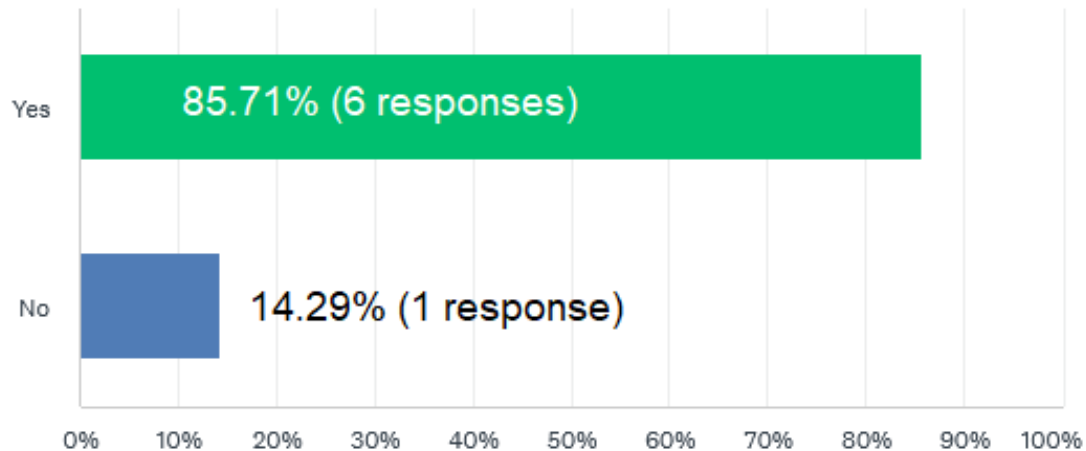
What other resources do you think would be helpful for yourself or other women with bleeding disorders?

- More knowledge
- More education on a primary doctor level for at least lab works to diagnose
- Just more knowledge, they say knowledge is power and that is very true for VWD. There's so much more to learn about it
- Better resources for our PCPs

Women Who Bleed

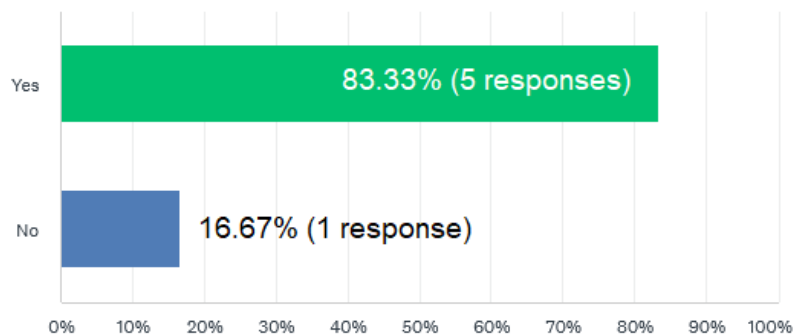
Do you currently have health insurance?

Answered: 7



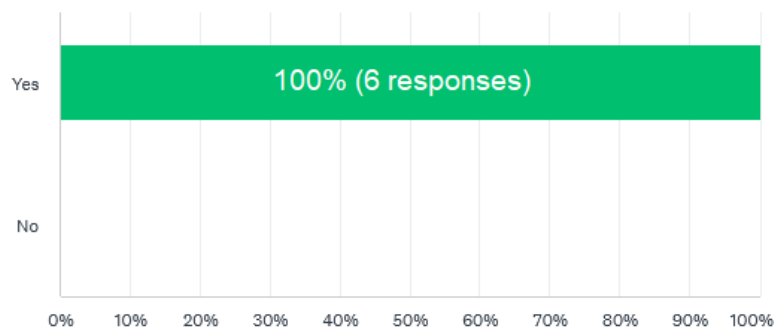
Does insurance cover the cost of doctor visits for you bleeding disorder?

Answered: 6



Does insurance cover the cost of medication for your bleeding disorder?

Answered: 6



Women Who Bleed

Respondents were asked to answer the following question in their own words. Their responses may have been modified for brevity and clarity. Not all respondents provided answers for the following question.

Are there any other issues you have experienced when seeking care for your bleeding disorder?

- HTC won't take us until the levels are checked and primary doctors aren't comfortable with ordering the labs.
- People sweep a lot of things under the rug, a lot of doctors don't care to listen to you.
- We drive 2 hours and it gives me anxiety. By the time they run the test my numbers are close to normal or normal compared to the test run close to home.
- Wait times to see provider.



Women Who Bleed

Survey Synopsis

While this survey is being used as a steppingstone to determine the needs of the women who bleed in the South Carolina bleeding disorders community, it provides many valuable insights into the barriers to care that women, in particular, face. It's interesting to note that while NHF, the CDC and even the chapter encourage all people with suspected bleeding issues or a familial history of bleeding disorders to seek care at an HTC, only 50% of the respondents said that they are treated at a treatment center and 62% of respondents are unhappy with their current treatment plans.

These numbers are also reflected in the number of medical providers that women go through before finding their current provider to treat their bleeding symptoms. 55% of respondents report having to visit 3-4 medical providers before reaching their current provider. While this number is not incredibly alarming, especially since we don't know the reason for the change, we also must consider that 62% of respondents aren't currently happy with their treatment plan. Should the respondents choose to continue the search these numbers may increase over time. This survey should be viewed as a snapshot in time.

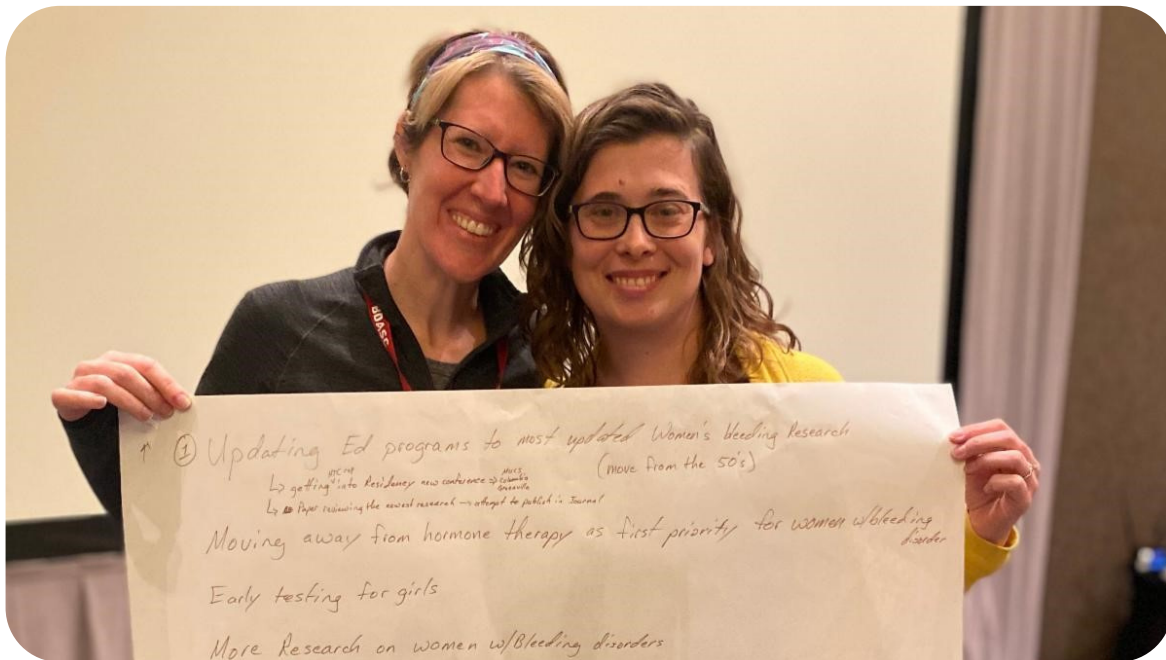
After the Health Equity Summit, it was brought up that women are often given hormonal contraception as the solution to their bleeding. Many women have said that they do not see this option as the choice they should have to make but is often their only option. According to the survey, 25% of respondents shared that the prescribed or recommended treatment for their bleeding disorder was hormonal contraception, whereas 83% of respondents said that they experienced heavy menstrual bleeding. This leads us to ask more questions. An additional survey may be required to account for those women who currently menstruate vs. those women who no longer menstruate.



Women Who Bleed

Survey Synopsis

It also begs to answer the question, how many of those respondents were already on hormonal contraception, and how many were on hormonal contraception for reasons outside of bleeding, as a practitioner may not suggest that as a treatment option if it's already being used. This could help us correlate if hormonal contraception is as helpful as it is believed to be or are there other treatment plans that could be more beneficial.



Another striking result is that when asked what other resources would be helpful to yourself or other women with bleeding disorders, the most suggested resource was education/knowledge. In looking at some of the other data, specifically when asked what bleeding disorder others in their family had been diagnosed with, there were 33% of respondents that replied “Hemophilia” but didn’t specify a type, and another 22% that replied “VWD” but didn’t specify a type.

This does not seem to be uncommon within the bleeding disorder community, but it begs the question, are we educating patients/community members well enough? Where is the disconnect? Maybe, the way to remove the barriers is just to provide the right people with the right education. These questions and more will be addressed in the coming months/years as we continue to ensure that every member of the South Carolina bleeding disorders community is able to receive quality treatment care, education, and support.

Summit Conference Evaluation Summary

The Survey was taken by 22 individuals or family members. The percentages are rounded and no unsatisfied remarks were made.

1. How would you rate your overall experience at the event?

Very satisfied- 59%

Satisfied- 31%

Neither satisfied or dissatisfied- 9%

2. How would you rate your experience with the registration and on-site check-in process for the meeting?

Very satisfied – 68%

Satisfied- 27%

Neither satisfied or dissatisfied- 4%

3. How would you rate the opening presentation?

Far above average – 36%

Above Average- 36%

Average- 31%

4. How useful did you find the information from the opening dinner presentation, "Positive Healthcare Outcomes Begins with Access to Treatment Care," presented by Dr. Stephanie Ambrose?

Extremely useful – 52%

Very useful- 23%

Somewhat useful- 19%

Not so useful- 4%

5. How useful did you find the information from the Saturday-morning opening presentation, "Meeting the Needs of All - What Keeps Payers & Advocates up at Night", presented by Michelle Rice?

Extremely useful – 55%

Very useful- 30%

Somewhat useful- 15%

6. How useful did you find the information from the Saturday-morning presentation "Health Equity, Diversity and Inclusion Overview," presented by Dr. Keri Norris?

Extremely useful – 60%

Very useful- 40%

Summit Conference Evaluation Summary

7. How useful did you find the information from the Saturday-afternoon presentation "Access to Care and Treatment: The South Carolina Hemophilia Treatment Centers - Part 2 Health Disparities and Engagement within Treatment Care"?

Extremely useful – 35%

Very useful- 50%

Somewhat useful- 15%

8. How useful did you find the information from the Saturday-afternoon presentation "National and Local Policy, preparing for the South Carolina Legislative Session: Addressing Health Equity, Diversity, Inclusion and Access to Care and treatment for all rare bleeding disorders," presented by Industry Stakeholder Partners and Josie Gamez.

Extremely useful – 30%

Very useful- 60%

Not so useful- 5%

9. How useful did you find the information presented in the Saturday Dinner Presentation, "Protecting our Mental Health," presented by Debbie De La Riva?

Extremely useful – 75%

Very useful- 15%

Somewhat useful- 5%

Not so useful – 5%

10. How useful did you find the information from the Sunday morning presentation "The Power of Story Telling," presented by Keri Norris?

Extremely useful – 50%

Very useful- 35%

Somewhat useful- 10%

Not so useful – 5%

11. How useful did you find the information in Wrap-Up session, "Wrapping it up! HEDI Working Group breakouts," presented by BDASC SME's Leadership and HEDI Participants?

Extremely useful – 47%

Very useful- 42%

Somewhat useful- 5%

Not so useful – 5%

Summit Conference Evaluation Summary

12. How satisfied were you with the programming provided by BDASC to entertain the Children?

Very satisfied- 50%

Satisfied- 31%

Neither satisfied or dissatisfied- 18%

13. How satisfied were you with the programming provided by BDASC for your teen?

Extremely useful – 26%

Very useful- 31%

Somewhat useful- 31%

Not so useful – 10%

14. How useful did you find the information you received at the exhibit's hall?

Extremely useful – 55%

Very useful- 5%

Somewhat useful- 27%

Not so useful – 11%

15. How satisfied were you with the location and hotel facilities?

Very satisfied – 15%

Satisfied- 63%

Neither satisfied or dissatisfied- 10%

Very dissatisfied – 10%

The 2022 Health Equity Family Advocacy Summit was attended by 144 individuals; to include 16 guests speakers, 17 Industry representatives, and 37 bleeding disorders families in South Carolina, all members of BDASC. In addition, 21 children and 17 teens were introduced and educated in age appropriate advocacy skills.

Additional comments were added throughout the survey which are being shared in their entirety. Our goal is to not leave any voices unheard.

General Comments

Please continue efforts encouraging inclusion, Great Information, well organized
The programs were very educational, Great educational opportunity. Learned a lot of new things.

This summit was well developed and had the right people at the table to help move forward with health disparity in the hemophilia community.

Shorter sessions needed, Great Job, Well organized, nice gift, information packet had what we needed, Kicked off the event nicely, nice opening dinner.

Presentation by people who experience health disparities was great to have

Dr Ambrose presentation: This was a fantastic update

Sat. Morning Session Panel: This may have been my favorite presentation, great to make connections with the speakers on the panel, Having DHEC and Insurance in the same room was great. It really sounded like BCBS really did want our input, and were trying to put the patient first. The panel all worked well to get their messages across, Great presentations

Access to care, part 2: Awesome information, I really loved and enjoyed this session, Dr. Gilbert did a great job sharing what's to come to their office

National Policy Updates: Very positive presenter

On Mental Health Presentation: Great Speaker, Fabulous!!! Great presentation, so calm and powerful, very important topic and great to have at all events. Great stories, Good to see the whole community involved. Would have loved to see more of the whole community there.

This was amazing! I like the teams working together, Excellent Group Input. Good to provide a debrief of the data and next steps, Liked hearing from the community Great involvement, Great way to get the community involved and give ideas I feel like this part (last session) is the most engaging and beneficial. Providing the community, the opportunity to present their solution was eye opening. In my opinion, I always like more of the round table format vs a presentation. It feels more beneficial to share ideas with those facing similar barriers.

On Children's Program: Great Job, the ducks were a hit, support staff were wonderful. My kids were happy with both days.

On Teen's Programming: They told me some of the sessions were boring, glad that we engaged them to use their voices.

Exhibits: Seems like less than usual attended, loved factor man, there are some energetic and friendly reps, which is great. I was surprised to find that many left early on Saturday and did not stay for the dinner and evening.

Venue: Cannot wait to go back to Myrtle Beach, location was great, liked location, hotel seemed disorganized. Loved the hotel location. Got my walking in. Was not so satisfied by the internet, very hard to connect and share our experiences and other things. Hotel was a little dated, dingy and noisy. Not as nice as the Greenville Embassy we normally stay at. Loved the location, did not love the hotel. Loved walking and stretching our legs after sitting in the conference.