



FTNN NEWS

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LETTER FROM THE FTNN PRESIDENT

Amy Powne, MSN, RN, PCNS-BC



DEVELOPMENT OF A PERSON CENTERED SCALE FOR FETAL CARE CENTERS

by Abigail Wilpers and Katie Francis



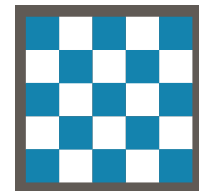
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EDITORIAL



Letter from the Fetal Therapy Nurse Network President- Amy Powne, MSN, RN, PCNS-BC



Dear Fetal Therapy Nurse Network members,

I hope this message finds you well and in good spirits. I am truly grateful for the opportunity to serve as your newest FTNN President. It is an honor, and I am eager to work alongside each of you to further the mission and goals of the Fetal Therapy Nurse Network. Together, we can continue to make a positive impact in the field of fetal therapy nursing care and strengthen our network's connections and contributions.

I want to take this moment to share with you my aspirations for the future. Our network has always been driven by a shared commitment to advancing the field of fetal therapy nursing care. We have made remarkable strides in providing exceptional care to our patients and families. However, as we look ahead, I believe that there is still much more we can achieve by building and strengthening relationships within our network.

The diverse and talented members of our network are spread across different fetal therapy centers throughout the United States. Each center brings unique perspectives, experiences, and expertise to the table. By fostering deeper connections between these centers, we can unlock a wealth of knowledge, insights, and best practices that can ultimately benefit the patients we serve.

My vision for the next two years is to create a more cohesive and interconnected community of fetal therapy nurses and healthcare professionals. I want to encourage open dialogue, collaboration, and the sharing of ideas and experiences. By doing so, we can address the challenges we face more effectively, find innovative solutions, and continue to elevate the standard of care in fetal therapy.

To achieve this, the FTNN will continue to facilitate opportunities for members from different centers to come together, exchange knowledge, and learn from one another. Your input, your experiences, and your willingness to collaborate are what will make this endeavor truly impactful. I encourage every one of you to join me on this journey of building stronger relationships within our network.

Together, we can continue to make a meaningful difference in the lives of the families who entrust us with their care. I am excited about the possibilities that lie ahead and am confident that we can achieve great things.

Please do not hesitate to reach out to me or our BOD if you have ideas, suggestions, or if you would like to play a more active role. Your voice matters, and your involvement will shape the future of the Fetal Therapy Nurse Network.

Thank you for your dedication to the field of fetal therapy. I am looking forward to our collective efforts and the positive impact we will undoubtedly have on patient care.

~Amy



Development of a Person-Centered Care Scale for Fetal Care Centers

by Abigail Wilpers, Ph.D., WHNP-BC and Katie Francis, MSN, RNC-NIC



This past September in Sweden, Dr. Abigail Wilpers and Katie Francis shared findings from the first joint study conducted by the North American Fetal Therapy Network (NAFTNet) and the Fetal Therapy Nurse Network (FTNN). The shared goal for this research was to develop and validate an instrument that measures person-centered care (PCC) in fetal care centers (FCC). Below is a summary of Abby and Katie's presentations.

Dr. Abigail Wilpers: What is person centered care? PCC is care that is respectful of and responsive to an individual's preferences, needs, and values. This is the care we all strive to provide. Sometimes you can really feel when you've provided that to a patient and their family, even when their health outcomes might not be optimal. And that's because PCC helps patients to have a positive care experience, which can help them participate in their care, set realistic expectations, and cope with the loss of a normal pregnancy. And while existing instruments like the Person-Centered Maternity Care Scale or the Person-Centered Prenatal Care Scale can measure some aspects of this concept in fetal care centers, they do not capture the novel complexities and nuances of patients' experiences in fetal care centers, such as being cared for by a large multidisciplinary team or undergoing maternal-fetal surgery. So there is a need for a comprehensive instrument that includes all aspects of person-centered care, tailored for people receiving care from specialized fetal diagnosis and treatment centers. Therefore, we conducted a study to develop and validate an instrument to measure quality indicators of PCC in FCCs across the US.

Developing an instrument is an iterative, multistep, and multimethod process. Initial items were developed based on literature and input from clinicians and former patients. A Delphi study involving 16 experts was conducted to validate the content and construct. Through three rounds of online questionnaires using open-ended questions and Likert scales, consensus on item clarity and relevancy was established. The resulting items were then piloted with 258 former fetal care center patients from across the U.S. via a web-based survey. The 3 aims resulted in the PCC-FCC Scale – a 28 item, 2 factor solution. What are the factors? We interpreted Factor 1, as the concept of feeling “cared for” which focused on respectful and compassionate caregiving tasks and includes the technical competence and effective communication of the health care team, and Factor 2 as the concept of feeling “cared about,” which focused on meeting the health-related quality of life needs of the patient.

In summary, the data supported content, construct, and concurrent validity. The manuscript describing the psychometric findings of the pilot study is currently under review.



Development of a Person-Centered Care Scale for Fetal Care Centers

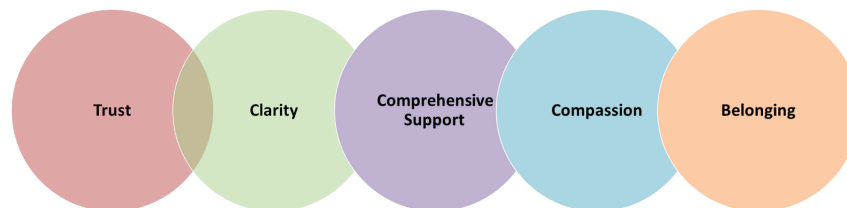


Fetal Therapy Nurse Network

Abigail Wilpers, Ph.D., WHNP-BC; Mary T. Austin, MD, MPH; Mert Ozan Bahtiyar, MD; Katie Francis, MSN, RNC-NIC, CPNP; Stephen Emery, MD; Diane Wall, MSN, RN, CNE, CPLC; Lonnie Somer, BS; Marney White, Ph.D., MS; Charlotte Wool, Ph.D., RN.

Katie Francis: Our team saw this study as a unique opportunity to also listen to the stories of former FCC patients. So, at the end of the PCC-FCC survey, we also asked, “Is there any other information about your care experience that you feel is important to share to help us measure and enhance care quality?” Our goal was to further characterize aspects of person-centered care in fetal care centers. 71 of 258 (27%) pilot study participants answered this open-ended question. Guided by the tenets of Interpretive Description, all the participants’ comments were read, and a preliminary coding structure was developed which was independently reviewed by the other members of the research team to gain additional insight from a lived-experience and clinical experts. Using thematic analysis, codes were then collapsed into categories, then themes and subthemes. Preliminary findings were again sent to the research team to verify conceptual fit of the original data. Broad analysis of the 71 comments showed varied responses, with most comments being positive in nature. Five preliminary themes were identified: Trust, Clarity, Comprehensive Support, Compassion, and Belonging.

One particularly exemplary quote demonstrated the five themes.



“....My husband and [I] had a meeting with every provider that would take part in our son's care: cardio, neuro, neonatologist, NICU nurse, palliative. It was amazing to hear each specialty speak and formulate a plan together. The compassion in that room was palpable. We knew step by step what we could expect and what would happen if something changed. It was the best experience I could have hoped for in a very stressful time... A week later we received a sympathy card from our fetal care team signed by all the physicians, coordinators, and nurses...”

This quote supports the idea that by fostering an environment of person-centered care made up of trust, clarity, comprehensive support, compassion, and belonging, even with the saddest of outcomes, a positive care experience can be achieved in an FCC.

Unfortunately, there are times when compassion fatigue is real and we fall short. Some examples quotes include:

- *I felt like we were talked around not to.* They were great with clinical information but *not about our wellbeing and mental and emotional state.*
- I will be dealing my entire life with diagnosed PTSD from the whole experience. It wasn't all bad, just a lot of *casually stating horrible things* about me and my baby that were extremely worrisome.

How many of us have been going through a busy day as usual, and we or our colleague walk into a room and say something like “ok so I see that your baby has been diagnosed with...” Likely a condition your site has seen so commonly, that talking about the diagnosis and prognosis becomes routine. These are some of the most painful words our patients may ever hear. Even though we may show empathy and compassion at other points in our care, these casually stated comments can be harmful.

Our next steps are to further develop the preliminary themes of person-centered care in a fetal care center. We will use these themes to identify any concepts that may be missing from the PCC-FCC scale.



FTNN NURSES at IFMSS 2023



At this year's annual International Fetal Medicine and Surgery Society (IFMSS) meeting in Visby/Stockholm, Sweden, members of the Fetal Therapy Nurse Network had the opportunity to share their work on an international stage. There were 4 presentations by FTNN members on day one, session one of the meeting.

- Dr. Abigail Wilpers** - Developing a person-centered scale for fetal care centers
- Katie Francis** - "The compassion in that room was palpable"; Patient's experiences in U.S. fetal care centers
- Bonnie Zapolin and Kassie Merrill** (licensed social worker) - Specialized childbirth education for pregnant persons with diagnosis of fetal anomalies
- Katie Schmidt** - Supporting patients & families with a fetal spina bifida advanced practice nurse program coordinator

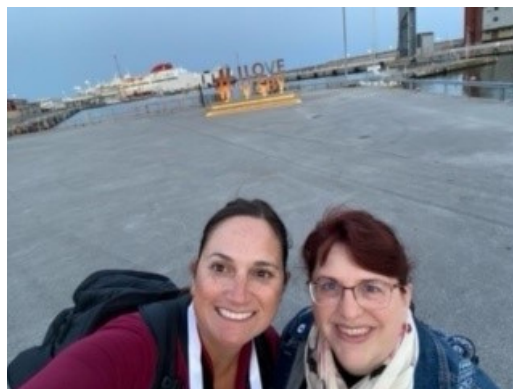


FTNN had another presenter on day 2 of the meeting.

- Kristen Gosnell** - Fetal pleural effusions and hydrops: Cause and effect determines prognosis
- And in the final session of the meeting,
- Amy Powne** - What happens in Cabo shouldn't stay in Cabo: our lessons learned



SWEDEN WAS AMAZING, the hosts did a wonderful job balancing science with incredible social activities, and ABBA!
Visby, Sweden: 3 days, 11 Scientific sessions, dinner in the medieval St. Nicolai church ruin, bus tours of the island, Studio 54 night club party
Stockholm, Sweden: 1 day, 1 Scientific session and business meeting while cruising the Stockholm Harbor area aboard the Teaterskeppet, theater ship. Finishing the week with a gala dinner at the Stockholm City Hall in the venue that hosts the Nobel banquet.



IFMSS 2024 Ireland... FTNN, let's see you there!



What is FTNN Working On? Committee and Working Group Projects

Publications Committee:

Currently, the ongoing project is bi-annual publication of the FTNN newsletter. The committee is actively seeking new members to help with creating content, writing, and formatting the newsletter. Our next newsletter will be published in May 2024. Anyone interested in joining may contact Barb Eichhorn at FTNNBoard@gmail.com.



Education Committee:

The newly established Education Committee had its first meeting in last month. Current projects include, acquisition of contact hours for FTNN educational offerings, and collaboration with the Orientation and Competency working group. Future projects the committee would like to tackle include, conducting a member survey to ascertain what educational offerings members are most interested in, creation of online learning modules, and development of an FTNN full day conference. This committee has a lot of work in its future and is in need of additional members. The committee is planning to have regularly scheduled monthly meetings. If you are interested in joining, please contact Allie Wayne at FTNNBoard@gmail.com.

Orientation and Competency Working Group:

Currently, this group is working to establish a template for the creation of checklists/competencies. The plan is to create materials that are specific to fetal care nursing. The long term goal of the working group is the development of orientation checklist and competency resources for the use of member centers. Orientation materials and competencies will focus on knowledge, skills, and abilities in: 1. The patient population/maternal fetal disease processes; 2. Conditions and diseases (maternal and fetal); 3. Equipment; 4. Procedures; 5. Professional practice. The group plans to target the Fetal Nurse Coordinator position with the initial checklists/competencies. This group is closed to new members at this time.



AROUND THE BOARD

updates from the Board of Directors



Membership Chair

Kristine Rimbos, MS, RNC-OB, NE-BC
For inquires email: Kris at FTNNBoard@gmail.com



Governance Chair

Mickey Johnson, MHA, RN
I am so excited to see everyone at the October 19, 2023 FTNN in-person meeting and to attend the Board of Directors strategy session.



Public Relations Chair

Betsy Van Etten, BSN, RNC-OB
If you have not already done so, check us out on social media! X (formerly Twitter): @NurseFetal, Facebook: Fetal Therapy Nurse Network, and our NEW Instagram page: @FetaltherapyRN



Secretary

Sarah Smith, BSN, RN, CLC
If you would like a copy of any meeting minutes contact our FTNN Secretary.



President Elect/Publications

Barbara Eichhorn, BSN, RN
I'm continuing to seek Publications Committee members and/or anyone interested in working on the newsletter.
The August Coffee talk was a great success, thanks to all that were able to participate. The next Coffee Talk will be in early December so everyone be ready to have a Peppermint Mocha while you join us to discuss...topic to be decided at our October Member meeting. Hope to see you there!



Research Co-Chairs

Abigail Wilpers, PHD, WHNP-BC and Kristen Gosnell, MS, RN Members of the Research Committee have been hard at work with NAFTNet on their proposal for the next phase of the Person-Centered Care Scale for Fetal Care Centers! This phase will be a follow up study to examine clinical outcomes and sociodemographic factors associated with experiences of person-centered care at fetal diagnosis and treatment settings. Barb Eichhorn, Dr. Wilpers, and their multi-center team have completed the systematic review of the literature to better understand potential disparities in diagnosis timing for fetal conditions. The manuscript is in development and will be submitted for publication this year. Stay tuned for our next journal club, and as always, submit your research ideas for discussion and support!



Education Chair

Allie Wayne, MSN, RN, RNC-NIC
Exciting educational opportunities coming your way! FTNN will now be offering education activities for contact hour credit at all upcoming in person meetings. All members will be receiving a survey in November to help guide member's areas of interests for upcoming educational topics and presenters. Lastly, the Education Committee is looking for new members! Please contact Allie Wayne at FTNNBoard@gmail.com if you are interested in learning more! .

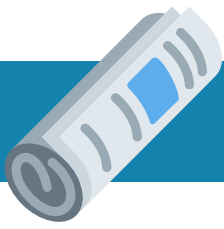


Treasurer

Katie Francis, MSN, CPNP
We are on track to meet the FTNN budget in 2023. The board continues to evaluate our financial targets with ongoing needs assessments, with an emphasis on how we can enhance FTNN offerings for all members. If you would like more information about FTNN's finances, please email our treasurer.



Email any FTNN BOD member at our group email:
FTNNBoard@gmail.com



Member News

FTNN MEMBER MEET UP

If you are attending SMFM in 2024, mark your calendars for the **SMFM FTNN Member Meet Up**. It will be held from 8 am to 10 am on Tuesday, February 13, 2023. Details on location of meet up will be announced as we get closer to that event.

PRESENTATIONS

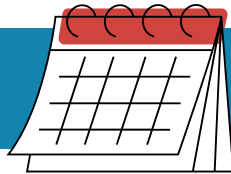
Shurki Jumale, MSN, RN-CLE and Abigail Wilpers, PHD, WHNP-BC recently participated as panelists in *Fetal Conditions Community Conversation*. A community conversation about fetal conditions, facilitated by a group of nurses working in maternal-child health. Organized by SisterSong Women of Color Reproductive Justice Collective.

PUBLICATIONS

Mickey Johnson- *Establishing a Fetal Center in a Freestanding Pediatric Hospital*
<https://publications.aap.org/neoreviews/article-abstract/24/8/e471/192861/Establishing-a-Fetal-Center-in-a-Freestanding-redirectedFrom=fulltext>

Debra Watson Smith- *Postnatal Myelomeningocele Repair in the United States: Rates and Disparities Before and After the Management of Myelomeningocele Study Trial*
https://journals.lww.com/neurosurgery/Fulltext/9900/Postnatal_Myelomeningocele_Repair_in_the_United.820.aspx?casa_token=kNA8R_ci_b4AAAAA:2Kd8TB5zD72a5Ft1CxUuNMOSfIKy2mzY9tDDMq9icV8PddHuaMRqiCMHUOM-j_8qMsi_mRjlujH_VPmnrUJcRwfG

Abigail Wilpers- *"We All Want to Be Able to Tell You Something Hopeful": Clinicians' Experiences Providing Maternal-Fetal Surgery Counseling*
<https://karger.com/fdt/article-abstract/doi/10.1159/000531535/845171/We-All-Want-to-Be-Able-to-Tell-You-Something-redirectedFrom=fulltext>



Upcoming Events



FRIDAY, DECEMBER 1, 2023
FTNN Coffee Talk - topic to be decided at member meeting on 10/19/2023
12:00 PM - 1:00 PM (EST)
Join us for our virtual [FTNN Spring Member meeting April 2023](#).
More details will be available on our website soon.

SAVE THE DATE! SPRING MEETING: APRIL 2024



To register for NAFTNet meetings: Non-NAFTNet members: fMMC Consortium and RAFT work meeting Registration Form | North American Fetal Therapy Network (NAFTNet)
NAFTNet members who have log-ons: Login | North American Fetal Therapy Network (NAFTNet) then under NAFTNet members, go to meetings and register.
For NAFTNet registration questions, please reach out directly to NAFTNet. Note, some NAFTNet website content may be blocked on work computers.



www.awhonnconvention.org



www.ifmss.com



<https://www.chop.edu/events/fetal-firesides-virtual-cme-lecture-series>



EDITOR
Barbara Eichhorn, BSN, RN
Publications Chair
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CONTRIBUTE TO THE FTNN NEWSLETTER!

The FTNN Newsletter is made for and by our members! A special thank you to everyone who contributed ideas and content to this issue. Thank you to the FTNN board of directors for reviewing and editing the final product. Please write to the editor with content or ideas for next issue!



Happy Fall FTNN!

I recently looked up the word engagement in Meriam-Webster and 2 of the listed definitions really caught my eye.

3a: the act of engaging; the state of being engaged; b: *emotional involvement or commitment*

4: *the state of being in gear*

These two definitions of the word capture how important member engagement is to both the member and the organization. For the member that is engaged, there are feelings of belonging, empowerment, and pride in the accomplishments of the organization. This is *emotional involvement or commitment*. For the organization, having engaged members strengthens the organization as a whole, and fosters growth and development. In other words, keeps the organization *in gear* and moving forward.

Why am I on a soap box about engagement, you may ask? Well, for 2 reasons.

The first reason is I'd like to promote committee membership. We have several FTNN committees in need of members. The Committee Chairs will be available to speak with you at the in person meeting in Chicago on October 19, 2023, to discuss what membership in their committee involves. You can also email the BOD to inquire about our committees at FTNNBoard@gmail.com. I encourage everyone to consider joining one of our FTNN committees.

The second reason for my focus on engagement is to get everyone thinking about our Board of Directors elections coming up in the spring. We will have 5 positions up for election. Publications Chair (3 year term), Research Chair (3 year term), Research Co Chair (3 year term), Secretary (2 year term) and Membership (2 year term). Now is the time to start thinking about nominations for the spring elections. If you are not sure what these positions do or what the commitment would be, please reach out to the current board member. We would be happy to share more information regarding these positions.

I hope you all enjoy this edition of our newsletter and look forward to our Spring edition in May 2024.

-Barb





HEY FTNN MEMBERS



PRE ORDER YOUR OFFICIAL FTNN SWAG!

Show your pride in being a member of our great network of nurses!

NOTE: We need a minimum number of orders for each item before the items can be produced. Cost includes shipping direct to you (no tax charged).

Add your desired items and quantities to your cart and checkout. You will not be billed until we receive enough orders for production. When we do, we'll send you an email, asking you to complete your order and pay at that time.



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