



Congenital and Pediatric Heart Patient/Family/Professional Outreach via Social Medi

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BACKGROUND

Social media use by the general public has increased as a common source of information. The National Council of State Boards of Nursing and American Nurses Association have provided advice and caution about use of social media. Research indicates patients are using social media for:

- Information
- Support
- Comparisons
- Expression of emotions

Evidence suggests that it can impact:

- Well-being
- Self-management
- Communication
- Healthcare choices
- Privacy
- Relationships

American Nurses Association. (2011, September). Silver Spring, MD
National Council of State Boards of Nursing. (2011, August). Chicago, IL

PURPOSE

Observing families' use of blogs, Facebook groups and web sites, we elected to utilize social media to enhance support, education, research, advocacy, and information. Results of these strategies were assessed.

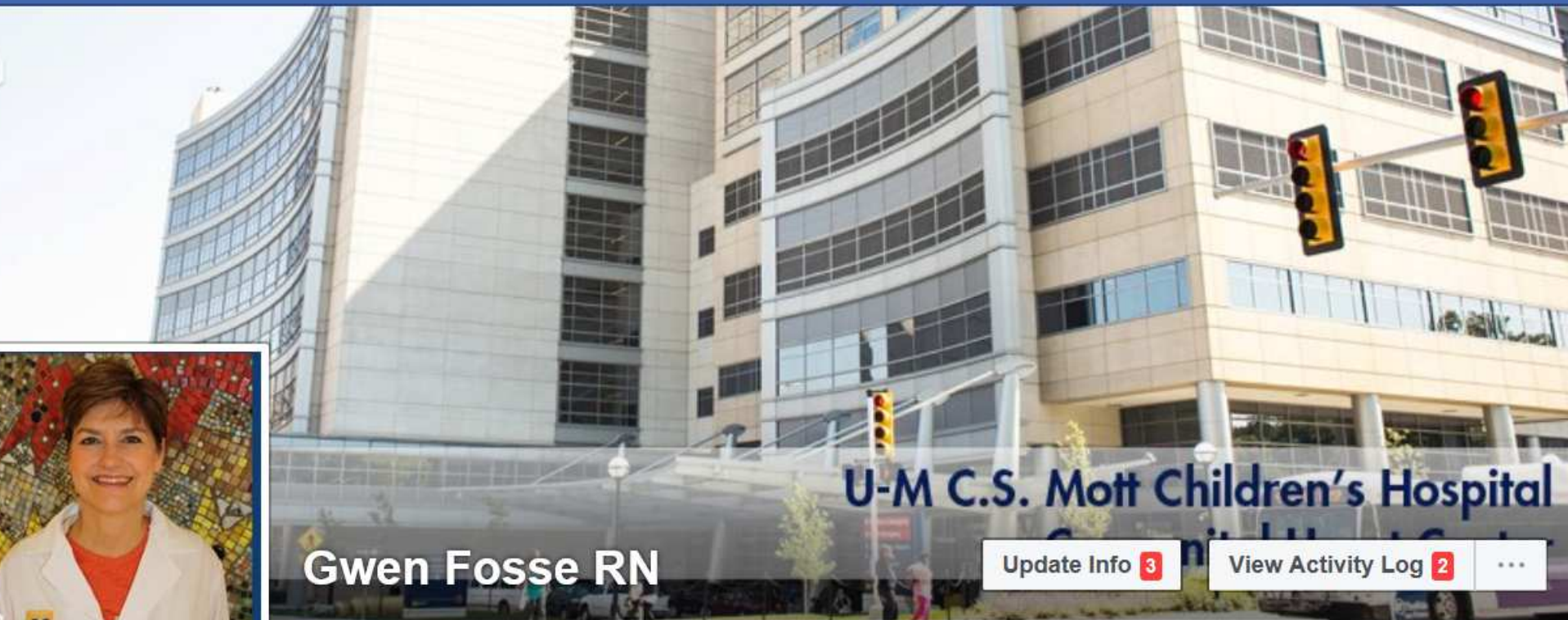
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METHODS


A Facebook page was created for the outreach nurse in 2013.


Appropriate national and regional congenital and pediatric heart disease social media organizations (e.g. healthcare, policy, non-profit parent groups) were identified to follow. Examples:

- C.S. Mott Children's Hospital
- American Heart Association
- Children's Heart Foundation
- Sisters by Heart
- Mended Little Hearts
- Project ADAM
- Michigan Department of Health & Human Services

Six regional groups (average membership 325) were joined.

Heart Families From Mott

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Heart Families From Mott

Public Group

About

Discussion


Members

Events


Videos


Photos

Shortcuts



Michigan Heart Families

Gwen FosseHomeFind Friends




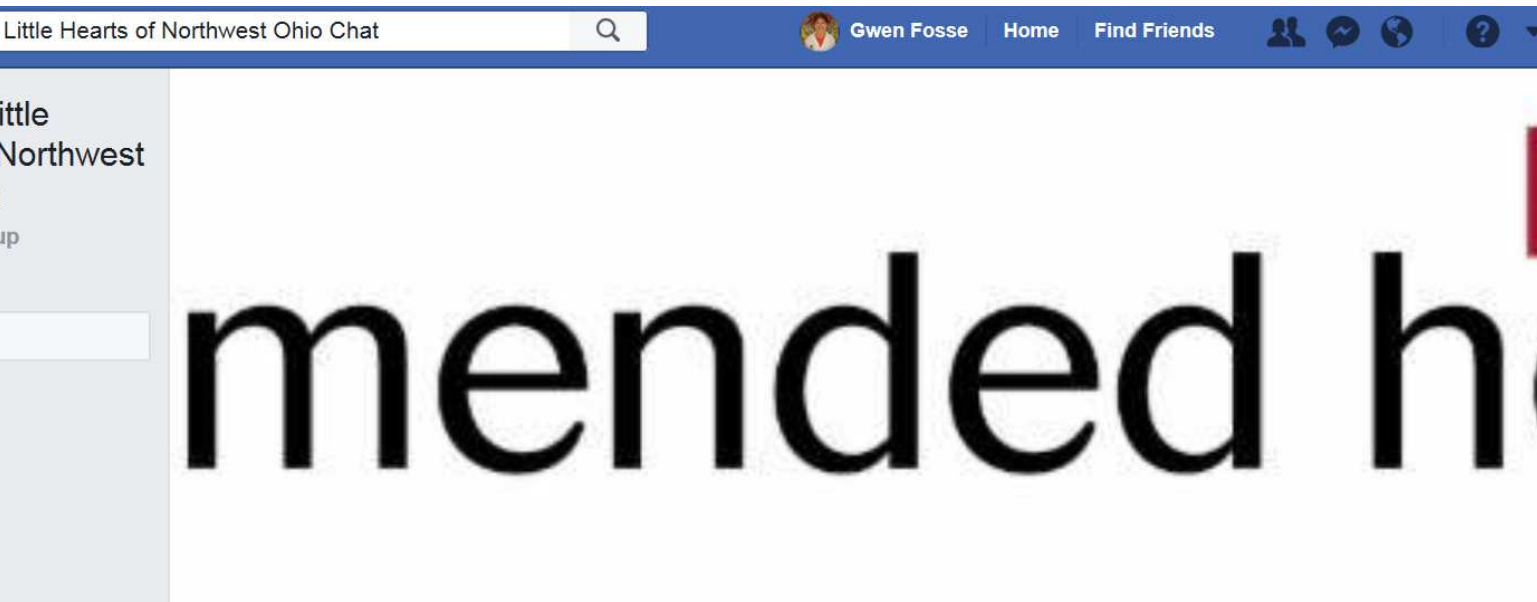
Michigan Heart Families

Public Group

Discussion

Members





METHODS (continued)

Experienced parental input was provided.

Professionals' and lay individuals' 'friend' requests were accepted although not all are 'followed' on Facebook to avoid losing focus.

Education, advocacy, invitations, services and research posts were created on the page and shared with sites.

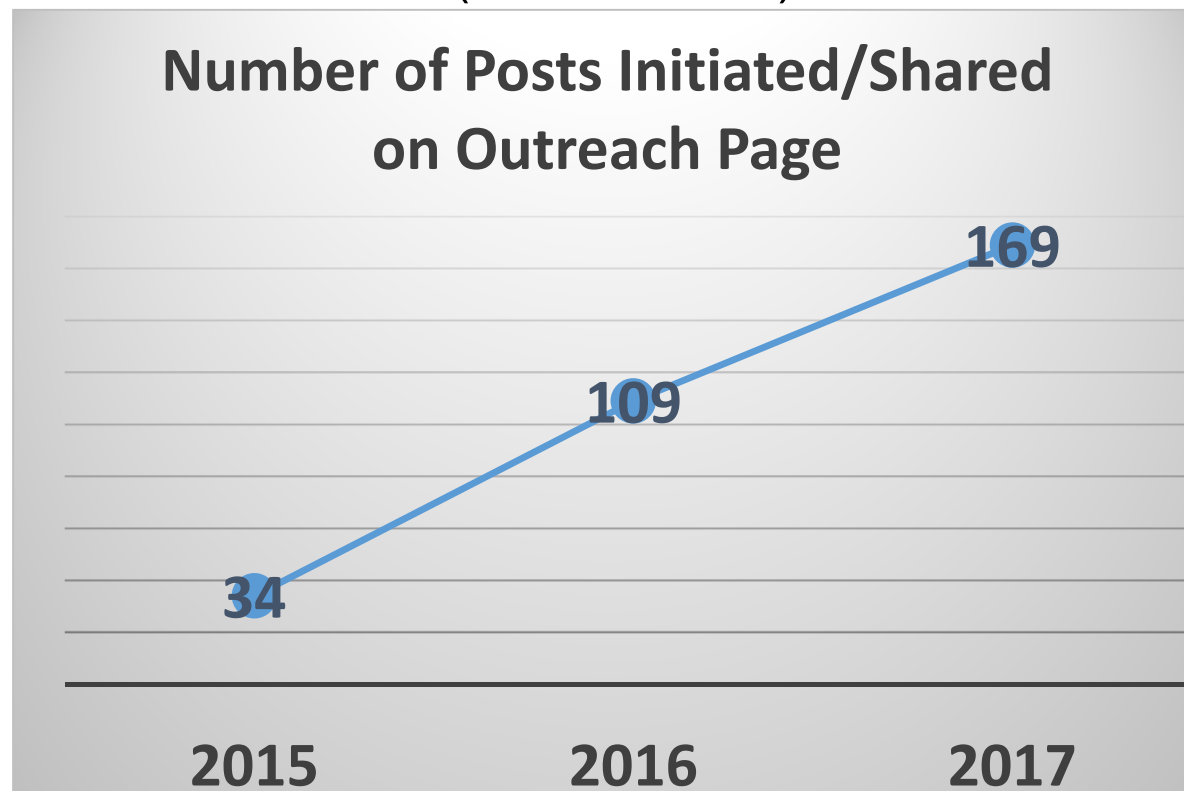
Comments and private messages have been utilized to respond to questions or intervene when potential misinformation occurs.

- Opportunity to address confusing or misleading information – public and/or private
- Avoidance of posting private medical information on social media
 - Different implications than what one encounters with using social media to obtain research information.

RESULTS

The Facebook page has garnered 175 friends, regularly reaches the 1948 members of regional groups and posts to national groups.

Regular posts initiated were 34 in 2015 (2.83/month), 109 in 2016 (9.08/month), and 169 in 2017 (14.1/month).



RESULTS (continued)

If a parent group leader posts a topic, attempts are made to avoid duplication on that site. Our center's parent advisors collaborate and, if preferable, the message is delivered by a parent.

Posts made by the outreach nurse from 12/1/2016 to 11/30/17 were evaluated. There were:

- 159 posts on the individual page with 770 'likes' (4.7/post).
- 243 shares or direct posts to the 6 regional parent group pages with 688 'likes' (2.8/post)
- For the total posts there were 1458 'likes' (3.6/post).
 - C.S. Mott page – general audience - >4000 'likes' on some posts
 - On group pages – updates on children are popular
 - On our page health info posts which were not specific to 'heart' were less popular posts
- The three top 10 'likes' lists (the outreach page, groups, and combined total) had 4 of the same topics

Top Ten List of “Likes/Loves”

| Date Posted | Topic of Post | Total "Likes" of Outreach + Group |
|-------------|---|-----------------------------------|
| 3/23/2017 | Senior surgeon acknowledgement with HLHS* | 94 |
| 7/17/2017 | World Congress Pediatric Cardiology & Cardiac Surgery (WCPCCS) - opening* | 66 |
| 7/28/2017 | WCPCCS - C.S. Mott Children's presence* | 65 |
| 12/15/2016 | Legislation passed for CPR education in schools* | 61 |
| 9/14/2017 | Adult Congenital Heart Association certification of C.S. Mott Children's | 43 |
| 1/30/2017 | Single Ventricle Clinic at C.S. Mott Children's | 41 |
| 2/13/2017 | Thanks to Pediatric Congenital Heart Association for CHD Awareness Celebration | 39 |
| 3/19/2017 | ECMO strategies research by PC4 | 36 |
| 5/6/2017 | Jimmy Kimmel - CHD and health policy | 34 |
| 11/2/2017 | American Heart Association - Innovations Forum | 27 |
| | *were in the 'Top 10' on each: the Outreach Page, the Group Page totals, and with 2 lists combined. | |



Gwen Fosse RN shared American Heart Association Mid-Michigan's photo.

December 15, 2016 · 🌐 ▼

Congratulations to everyone from C.S. Mott Children's Hospital - Project ADAM Michigan of University of Michigan was thrilled to be a part of making this happen!! www.mottchildren.org/projectadam for more information about "heart safe"! And, need info on "hands only" CPR??? For the Michigan Way: <https://www.youtube.com/watch?v=QLyxKFSwX5M>



American Heart Association Mid-Michigan

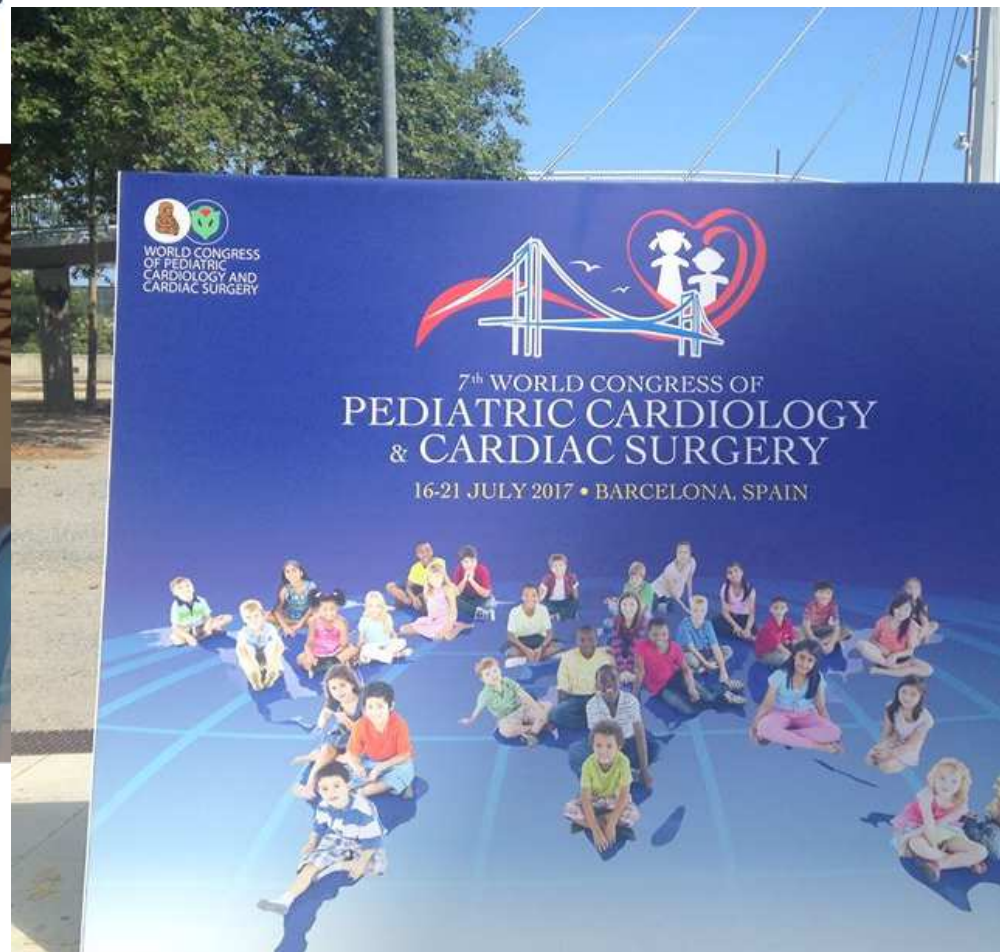
Page Liked · December 15, 2016 · Edited · 🌐

GREAT NEWS: The CPR in Schools bill passed late last night! Thank you to everyone for all your phone calls, emails, texts and support that helped to make this a reality. We have much to celebrate as Michiganders will be able to save many more lives through the years using CPR. Thanks to Sen Tonya Schuitmaker and Rep. Tom Hooker for their sponsorship of the legislation and support during this process! #CPRMI #AHAMI #HealthyMI #AHAWestMi #AHADetroit #AHAMidMichigan

wen Fosse RN added 2 new photos.

July 17, 2017 · Barcelona, Spain · 🌐 ▼

Games' begin! Members of the CS Mott Children's Hospital - University
Michigan Congenital Heart Center team in Barcelona with over 3000 others
from all over the world - together to improve kids' heart care all over the world!!
#WCPCCS2017



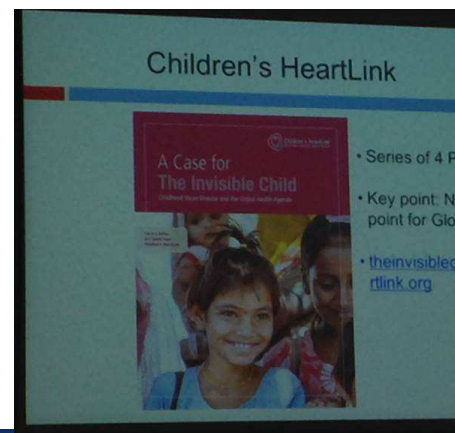
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Gwen Fosse RN added 6 new photos.

World Congress of Pediatric Cardiology and Cardiac Surgery 2017 is complete. Over 3000 people from 112 countries gathered in Barcelona as the world worked together for kids – so inspirational to see many professionals from C.S. Mott Children's Hospital U-M Congenital Heart Center contributing widely to the many avenues of collaboration – those who presented in Barcelona (Louise Callow, Brynn Dechert-Smith, Drs. Charpie, Gaies, Pasquali, Owens...) and all the professionals and patients behind the scenes, too. A global commitment was made to try to make care better for the 93% of our world's children who don't have access to adequate heart care. Our kids and adults with CHD in Michigan are so fortunate. And Dr. Carole Warnes' lecture, honoring Dr. Jane Somerville (the 'mother' of ACHD care), was a meaningful tribute to the resilience of and commitment to our many adults with CHD. During our entry and exit into the main auditorium the song that was regularly playing is by Mindy Gledhill with lyrics that say "...it's not about your scars, it's all about your heart..." What could be more perfect? Next world congress to be hosted by the USA in Washington DC in 2021. #wcpccs2017 #wcpccs2021



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Gwen Fosse RN

March 23, 2017 · 🌐 ▼



It has been an honor to witness Dr. Bove's contributions to advances in pediatric heart surgery!



Advancements in Treatments for HLHS Heart Warriors

How has treatment for those with hypoplastic left heart syndrome (HLHS) changed over the years? What new treatments are available? What does the future for HLHS Survivors look like? Tune in for answers to these questions and much, much more!

US3.CAMPAIGN-ARCHIVE1.COM

RESULTS (continued)

- There were 80 'shares' directly from the posts made by the outreach nurse.
- Additionally, shares are made by other national and regional organizations as they choose and the outreach nurse comments on and 'likes' others' posts, generating goodwill.

Tagging and hashtags

- Our tags and hashtags
 - #LittleHatsMI
 - #CHDAware
 - #conqueringCHD
 - #CPRinSchools
 - @SupportProjectADAM
 - @TheCHF
- From others
 - posts to our page
 - Tagging us

Additional Advantages

- When special messages are received they can be shared with appropriate individuals
- Comments from ‘friends’ tend to be very positive – having others see those reflections is advantageous for our center and supportive to families to see their team endorsed
- An opportunity to reacquaint with past families and to get updates
 - Outcome in patient with a syndrome and palliative surgery
- Compliments about our team can be shared
 - Nobody is “too big” to not enjoy a compliment

Announcements



Gwen Fosse RN shared University of Michigan Cardiovascular Center's post.

September 14, 2017 · 🌐 ▼

Happy day!!



University of Michigan Cardiovascular Center

September 14, 2017 · 🌐

Just announced: Our adult congenital heart disease program is the only one in Michigan, and among the first nationwide, to earn accreditation for our expertise in patient care.

More: <http://www.uofmhealth.org/.../michigan-medicine-earns-accredi...>

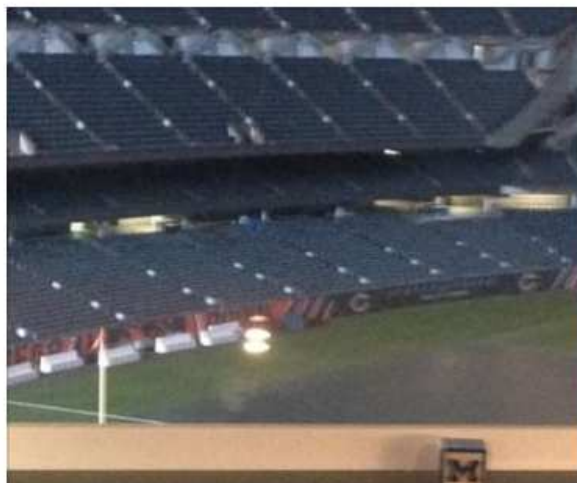
Sharing



Gwen Fosse RN added 5 new photos — with Gwen Paxson Fosse ...
at **Chicago Bears - Soldier Field**.

November 2, 2017 · Chicago, IL · 🌐 ▼

C.S. Mott Children's Hospital University of Michigan Congenital Heart Center team getting pumped at Soldier Field for AHA Heart Innovation Forum—preserving donor heart time, 3D printing of tracheal splints, evolving pacemakers to be powered by motion....."Bear Down" for #conqueringCHD!



Research



Gwen Fosse RN

February 21, 2017 · 🌐 ▼



Heart Month! A great time to encourage a CHD research opportunity!! Do you know someone between the ages of 12 and 19 years who has had a Fontan procedure for a single ventricle heart condition? If so, that person may be able to contribute to a very important research study funded by the National Heart, Lung, and Blood Institute. This study is being done at about 24 medical centers in the U.S., Canada and the Republic of Korea, including [C.S. Mott Children's Hospital](#) – Uni... [See More](#)



FUEL and FUEL OLE - Studies - Pediatric Heart Network

Current & Completed Studies, Coming Soon

PEDIATRICHEARTNETWORK.ORG



Like



Comment



Share

Advocacy

Gwen Fosse RN added 4 new photos.

February 28, 2017 · 🌐 ▼

This month concludes we want to give a shout out to some of the many that are doing fabulous heart safe work. Project ADAM Michigan at C.S. Mott Children's Hospital was privileged to represent Michigan Department of Health and Human Services to present Sturgis High School and Michigan Central High School with their MI HEARTSafe Schools awards. We know many schools have worked on CPR/AED drills including North Muskegon Public Schools. Michigan Central High School (Michigan) conducted CPR training. We were happy to see Michigan Central High School make progress in their journey to becoming a MI HEARTSafe School. Some great examples of the wonderful work that occurred this month thanks to the schools, the MI HEARTSafe Schools initiative and Project ADAM. Please let us know if you have more photos to share by emailing projectadam@med.umich.edu.





Gwen Fosse RN added 2 new photos.

April 23, 2017 · 🌐 ▼

Project ADAM Michigan of C.S. Mott Children's Hospital shouts out support of this last week of April as Michigan Student Athlete Awareness Month! Thanks to all who made this happen! And a shout out to MI HEARTSafe Schools - applications from schools are due by May 15, 2017.

www.mottchildren.org/projectadam can help schools become a MI HEARTSafe School. Being prepared for cardiac emergencies in athletes and for all students, staff & visitors is important for all schools. Email: projectadam@med.umich.edu for more information. [Project ADAM](#)





Gwen Fosse RN shared Pediatric Congenital Heart Association's post.

September 13, 2017 · 🌐 ▼



Pediatric Congenital Heart Association

September 12, 2017 · 🌐

PCHA is coming off a few days in Washington D.C. and we wanted to provide you with an update on the status of the Congenital Heart Futures Reauthorization Act. ...

[See More](#)



Congenital Heart Futures Act of 2017 (S.477/H.R.1222) - PCHA

Congenital Heart Disease Legislation In February, 2017, the Congenital Heart Futures Act Reauthorization Bill was re-introduced in the Senate (S.477) and House (H.R.1222) by legislative...

CONQUERINGCHD.ORG

Chat (Off)

Group Events



Gwen Fosse RN shared Colleen Schomaker's post.

September 26, 2017 · 🌐 ▼

What a great team representing C.S. Mott Children's Hospital Congenital Heart Center for the The Children's Heart Foundation SE Michigan walk!!! Great Team! Great Cause!



Gwen Fosse RN ▸ **The Children's Heart Foundation - Michigan Chapter**

May 17, 2016 · 🌐

As a member of TEAM MOTT I'm walking this Saturday for our girls and our grandchildren. They have a congenital heart condition called Long QT Syndrome that affects their EKG. Our thanks to Children's Heart Foundation for supporting research!! Join our team or donate for TEAM MOTT for the West Michigan Congenital Heart Walk in Kalamazoo - <http://events.congenitalheartwalk.org/site/TR/Walk/General...>

📍 Tag Photo

📍 Add Location

✎ Edit

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💬 Comment

➦ Share

👍 6

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Gwen Fosse RN shared **Jennifer Shaw Wardrop's** post.

September 11, 2017 ·  ▼

heart treasure" to see friends I knew as babies - now all grown up and
back - Courtland, Tyler Šajdák, Connor..... - and to meet new friends
with hearts and conquering hearts! Everyone really is a winner at the
Michigan Funky Heart 5K!! Thank you to all organizers, volunteers,
s, runners, walkers, donors and everyone who was there!
ringCHD at C.S. Mott Children's Hospital

...

Jennifer Shaw Wardrop added 2 new photos.

September 9, 2017 · 

While we planned to run the Funky Heart 5k as a family, with Devin getting sick
Connor and Brett attended. Connor placed 2nd in his age group and was able
of his nurses - 15 years later!

Fundraising



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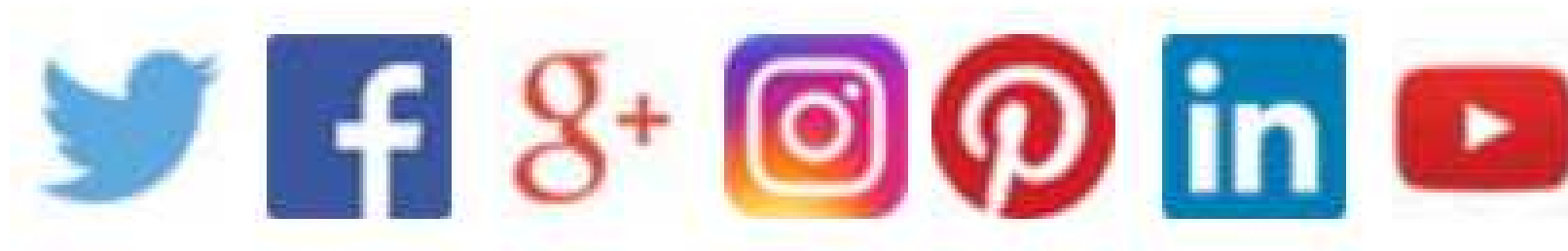


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CONCLUSIONS

- Creating this social media outreach presence has provided families with evidence of tangible engagement by our center.
- The ability to support shared missions of various organizations mutually strengthens all.
- Advocacy, education, access to care, research enrollment, intervening to provide accurate resources, and guiding the use of internet information can be furthered.
- A Facebook page establishes a unique avenue of communication to receive questions, constructive suggestions and treasured compliments and messages of gratitude that can be sent to our team.
- This approach has been appreciated by families and has proven to be a valuable outreach strategy for our center.

What's next?????



Thank you!

