

# Patient & Family NEWSLETTER

ISSUE #3 | JANUARY 2019

#### ANNOUNCING NEW FULLTIME EXECUTIVE DIRECTOR FOR THE GTC



Diane O'Toole GTC Executive Director

After a thorough search process by the hiring committee involving more than 40 candidates the GTC is pleased to announce that **Diane O'Toole** was hired as the new Executive Director.

She brings 20+ years of not for profit experience with her most recent stint in healthcare as the Executive Director of the American Nurses Association of Massachusetts. Diane's leadership strengths are setting

a vision, fundraising, building memberships, process improvement and human resource management. She holds a BA in Political Science and Psychology from Wheaton College and a Master of Public Administration from the University of Massachusetts as well as completing several certificate programs. Diane resides in suburban Boston.

Many thanks to the search committee for completing this task in a diligent and efficient matter. Having a leader of Diane's caliber in place will greatly propel the mission of the GTC.

Diane will be attending all committee meetings and will be reaching out to Board and Committee members in the next few months. ■

#### CALL FOR GTC PATIENT AND FAMILY CHAMPIONS

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The power of the patient and family voice in quality improvement initiatives is essential! We are looking for Patient and Family Champions that can help partner with the GTC to share the work that our quality improvement collaborative is doing to improve tracheostomy care everywhere.



Erin Ward, and son Will Patient & Family Committee Chair, GTC BOD

We are putting a call out to Member Hospitals and Healthcare Professionals, who are interested in getting your hospitals to enroll as members of the GTC, to help identify patient and family members who may be your most vital partners in helping to spread the work and advocate at your institutions to be a part of the Global Tracheostomy Collaborative.

If you know of a patient, family member, caregiver, or Family Advisory Committee member at your institution, and are interested in partnering with them, please encourage them to contact our Patient & Family Committee at <u>patientandfamilies@globaltrach.org</u>. We can provide mentorship, guidance, and support to help spread awareness and the importance of the GTC mission to improve tracheostomy care and increase patient safety for all.

#### PATIENT & FAMILY -FREE MEMBERSHIP!

- Share your stories and pictures to increase awareness worldwide.Learn how to connect with other patients and families.
- Access patient-centered resources globaltrach.org/join-us/patient-and-family-memberships/

# **PATIENT & FAMILY EVENTS**

#### **USA:** CHILDREN'S HOSPITAL OF NEW ORLEANS, LA AND TRACH MOMMAS OF LOUISIANA PATIENT & FAMILY EVENT

Children's Hospital of New Orleans Louisiana (CHNOLA), hosted a great event in May 2018 that celebrated children who have a tracheostomy and their families. They invited children who received a tracheotomy at CHNOLA in the last couple of decades! There were families that came with children of all ages. It was amazing to have younger kids meet older kids who are thriving with a trach just like them. They had games, food, prizes and tables set up with great information and resources. They even had tours of a fire truck. Trach Mommas of Louisiana (trachmommas.org) was happy to collaborate at this event displaying and talking about planning for hurricane season!



Trach Mommas of Louisiana showed families what an emergency bin and a Trach Go Bag should be stocked with at all times. The table had information and displays that challenged families to think about their emergency plan. Jessica Michot and Angéla Lorio, the founders of Trach Mommas of Louisiana, were on hand to answer questions and offer suggestions for effectively planning and evacuating in an emergency. In addition, they took applications for their latest initiative for automobile power inverters customized to be able to run home equipment safely in vehicles for long evacuations and vacations.

Trach Mommas of Louisiana provides 24/7 support

to anyone with a trach and their family to give hope and walk them through new situations, home and hospital visits to share community resources & give a hug and let them know they have been there as a mom (or with a trach themselves) and it will be ok. They have a huge warehouse of home medical supplies and a DME loan closet free to anyone in need and they do emergency prep and disaster relief. They also advocate at the state capital for services for those depending on technology to be well and live. Both of Angela and Jessica's sons go to Children's Hospital of New Orleans and see Dr. Kanotra, an otolaryngologist, who started a Pediatric Airway and Swallowing Clinic. They were excited to learn that CHNOLA was going to become a Member Hospital of the Global Tracheostomy Collaborative. This will mean a team approach to have best practices put into place at Children's of New Orleans, as they will be connected with a global network!

Trach Mommas is so excited to be collaborating with CHNOLA and we hope more hospitals in Louisiana and throughout the U.S. will choose to partner to promote best practices which greatly improves the quality of care of our kids!

#### UK: MANCHESTER UNIVERSITY HOSPITAL NATIONAL TRACHEOSTOMY SAFETY PROJECT'S 4TH IMPROVING TRACHEOSTOMY CARE MEETING

Shared by Barry Coe, ICU Charge Nurse and ITC Project Manager

I want to give you a quick summary of our 4th Improving Tracheostomy care meeting. We held this event at the Health Foundation HQ\*, in London, England on the 8th June this year (\*the health Foundation is charitable organisation that funds health care improvement projects). The meeting was attended by over 60 health care professionals from across the entire UK.

Prior to this event the ITC team at Manchester we were very lucky to visit and complete a grand round, with some of our esteemed colleges from the GTC. This included **David Roberson**, **MD**., GTC President, and **Vinciya Pandian**, airway nurse specialist from Johns Hopkins University hospital. We were very pleased to give our guests a tour of facilities at the University Hospital of South Manchester, and, David



gave a very well received presentation on quality improvement methods at our education centre.

At Our London meeting we were treated to a superb, powerful and inspirational, account of the challenges faced by a person with a tracheostomy and their family, by a wonderful gentleman and his wife from the US, **AI and Nan Smith** (GTC Board of Director Members)

The day was filled with lots of interesting and informative ideas of how to improve and maintian high standards of care for people and their families wth a tracheostomy.



Al Smith and **Elliana Kirsh, MD** Candidate of Harvard School, treated the group to a brillant duet of "what a wonderful world," and the with *Throaty affect* of the tracheostomy on Al Smiths voice, it really did sound like Louis Armstrong was singing to us. Overall, was a fantastic event focused on

improving tracheostomy care!

#### **AUS: FAMILY FORUM AUGUST 22, 2018**

On 22nd August TRAMS, VRSS (Victorian Respiratory Support Service) held a Winter GTC Tracheostomy Patient and Family Forum. It was a wonderful occasion where we received and update on our global tracheostomy community from our TRAMS manager **Tanis Cameron** as well as a video message from our patient and family committee lead **Erin Ward**. Our TRAMS senior speech pathologist Lucy Fritze facilitated a talk on developing resilience which generated key themes through group discussion. We also had some winter-warming fun by doing some drumming with a traditional West African drummer.

Included in the day was personal stories shared by our GTC members **Gabby Chessels** as well as **Sally and Jenny Messer** (see their stories on page 6).



This year, we gave all of our hospital and community patients hand-made cards congratulating them for thriving with a tracheostomy and acknowledging their strength, tenacity and perseverance. These beautiful cards were designed and made by Sally Messer, a tracheostomy patient in the Austin hospital and her mother Jenny. Patients and families had an opportunity to connect with one another, share stories, learn from each other and a strong sense of a tracheostomy community was created and sustained.

#### **SHARE YOUR PICTURES & STORIES!**

The GTC is seeking patients & families who are willing to share their tracheostomy story for the purpose of helping to educate the global community and promote awareness about life with a tracheostomy. You can actively participate in the GTC's mission to improve the quality of care for patients with tracheostomies around the world by sharing your story and promoting awareness. Visit: globaltrach.org/collaborate/patientsfamilies-portal/share-your-pictures-stories/

## PATIENT & FAMILY ENGAGEMENT EFFORTS

#### AUS: TRAMS TEAM AWARDED CONSUMER ENGAGEMENT AWARD



The TRAMS team was chosen as one of four finalists out of 17 applicants and received a Highly Commended Certificate. The certificate was presented to the TRAMS team at

the Consumer Engagement Award Ceremony on 17 October 2018. Nurse Consultant, **Christine Knee Chong** did a short presentation about the TRAMS hosted Patient and Family Tracheostomy Forums. View their poster that was created for the award

here: <u>http://tracheostomyteam.</u> <u>org/patients/</u>. Congratulations to the TRAMS Team!



#### UK: PATIENT ENGAGEMENT EFFORTS: NATIONAL TRACHEOSTOMY SAFETY PROJECT, MANCHESTER UNIVERSITY

The National Tracheostomy Safety Project at Manchester University, England, are continuing to collect data for their QI project and have over 600 questionnaires and interviews with patients and/or families about their experiences in UK NHS hospitals. They completed the Hospital Consumer Assessments of Healthcare Providers and Systems (HCAHPS) that measures patient perspectives of hospital care and



asks patients about their experience with staff, pain management, their care, and their impression of the hospital over all. This information gathered will be incredibly helpful in capturing the patient and family tracheostomy experience. Their plan is to show patient experience change over the 2 years that these sites have been GTC members. Below you'll find a wordly composed of the words found in the response to "What is good trachy care?"



The NTSP team from Manchester University has also been busy at work trying to empower the patient and family voice in care and have created some adult and paediatric videos

to share with the tracheostomy community, to hear experiences, and provide education and awareness. The team hopes that these videos will enlist the powerful support of patients and families to enable and driving positive change in tracheostomy care. Here is a view of the onsite filming crew working hard to capture patient Tammy's, voice and experience, as the ICU was temporarily transformed into a film set. Visit <u>tracheostomy.org.uk</u> to see more about their important work for tracheostomy patients and families.

The team from Manchester University has also led the development of National Paediatric Guidelines recently published in an **Anaesthesia** article "Multidisciplinary guidelines for the management of paediatric tracheostomy emergencies" Abstract

and article can be found at: <u>https://onlinelibrary.wiley.com/</u> <u>doi/abs/10.1111/anae.14307</u>



#### USA: THOUGHTS FROM A TRACH EDUCATOR – BY DIANE RANDALL

Being a tracheostomy educator means looking at many different situations. Does the family understand? Will they be able to take care of their loved one? Will they have the patience to educate others when they are in the home setting? What will they do if there is a weather emergency? Did I properly prepare them? Sometimes I feel like I am an overprotective parent preparing my child for the outside world.

But so many times, I have been so proud to watch the families excel in the tracheostomy and ventilator care for their loved on. It is such a sense of accomplishment to watch the patient to take part and become an important part of a family circle. It is even more special when those same families can use the knowledge given to them to trouble shoot and come up with solutions for new and different situations.

Patients and families have shared with me their ideas and insights on how to overcome different situations, and I almost always pass on these ideas to new families.

So, then the teacher becomes the student and things come full circle.  $\blacksquare$ 

#### WHAT IS THE GTC?

The Global Tracheostomy Collaborative (GTC) is a quality improvement collaborative that recruits hospitals to join us, to improve the lives of people living with a tracheostomy through implementing best practices around tracheostomy team care and standardization. Their outcomes are tracked through a world-wide confidential database.

#### WWW.GLOBALTRACH.ORG



International Tracheostomy Symposium

## **SAVE THE DATE**

5<sup>th</sup> International Tracheostomy Symposium Safer Tracheostomy Care Everywhere

### 11 October 2019 Melbourne, Australia

Sofitel Melbourne on Collins Melbourne, Australia

For updates, go to: www.tracheostomyteam.org



## Austin

Tracheostomy Review and Management Service (TRAMS)



# **PATIENT STORIES**



#### AUS: SALLY MESSER

Hi. My name is Sally and I live with my family in Drouin. I have a neurological disorder which has caused deterioration over time, particularly in the last two years. Despite ongoing medical problems, I went on to complete year 12 and become a dental nurse. However, I am currently an inpatient in the Austin Hospital due to acquiring

a tracheostomy on December 5th, 2017 at the Royal Melbourne Hospital.

This occurred in an emergency situation as I had developed an aspergilloma in my lung which compromised my airway. Having the tracheostomy inserted ensured that I now have a secure airway, supported breathing and bleeding could be better managed. Prior to this current hospitalization, I enjoyed living at home supported by my family, friends, carers, district nurses and an amazing G.P. I enjoyed going to the theatre, football and being involved in the disabled surfing association.

My other passion is card making, I sell the cards that I make to raise money to support my 4 sponsor children in Fiji via a charity known as "Hope for a Village". The money raised provides for their education, healthcare and daily needs. I also love cooking, often cooking for the family and making meals for people who are experiencing ill health which I am really looking forward to continuing when I get back home, and teaching mum to use the Themomix

I am really looking forward to transitioning back home with a full time care team that can help me achieve my goals and return to the things I love doing, and also my beautiful puppy named Lilly. Who is waiting for me. As you can see I have a photo wall in my room which is covered with photos and post cards from around the world and from my home town to remind me how love I am.



#### AUS: JENNY MESSER (SALLY'S MOM)

For me, it's been a learning journey, learning to live with a child with a tracheostomy... and that every person manages at their own pace. It's sometimes harder when it has been thrust on you suddenly without warning as it was for Sally. So it's important to give yourself time to come to terms with this

new normal... there has been grief involved for what you have lost that needs to be processed before you can again look to the future and determine how you can live well with it.

The most important thing that will help you to achieve this is teamwork between patient family and treating team. This includes the vital components of:

**Clear and Extensive Communication** – Never assume that those involved know anything. Keep talking to each other, listen to each other well, ensuring always that everyone understands the needs of the person with the tracheostomy, that everyone is on the same page.

**Respect** – The person with the tracheostomy may have lost their physical voice for a while – and can't communicate what is important to them and have a say in every aspect of their care. Sometimes family needs to be their voice for a time and they also need to be respected for their role in advocating for their loved one.

**Compassion and Empathy** – Especially important that the treating team and families try to put themselves into the shoes of the person living with this new normal, and care for them in the same way that you would want to be cared for if the roles were reversed. Take time to stop and think about how extensively this has changed their life, how powerless and vulnerable they now feel and be patient.

**Celebrate the Small Achievements** – For the person living with the tracheostomy they are actually not small they are huge and have potentially cost them

a lot to achieve. So, when they croak out that first word with the Passy Muir Valve on, that is awesome, because it probably took every ounce of energy, they had to make that sound.

**Be Problem Solvers – Not Problem Creators** - Every hurdle that arises is something to work together on overcoming. Be creative, because no matter what obstacle or issue, together we can achieve solutions.

**Persevere** – Rome wasn't built in a day this is going to be a long journey together both as family and as patient/treating team.

I would like to take this opportunity to sincerely thank Christine and Tanis for the help and support in equipping me to care for Sally in the light of her changed circumstances living with a tracheostomy and for Lucy who is helping Sally find her voice. I have also been grateful for the invitations to participate in the Critical Care Forum, Seminars, being introduced to the GTC and the early morning GTC WebEx's while being here at the Austin. The TRAMS team have been a great encouragement to both Sal and I.

As you can see from all the people present it is possible not only live with a tracheostomy but to actually thrive and live life fully step by step one day at a time.



#### USA: KIM COLASANTI (MOM) AND DAUGHTER VICTORIA

Tracheostomy is a word that we never thought we would ever be incorporating into our lives, but after a bronchoscopy revealed tracheomalacia in our infant daughter, Victoria, we knew it was the only choice. It was a very scary feeling knowing she would have to have a hole in her windpipe

to allow for more controlled breathing. Fears about keeping her airway safe and all the unknowns associated with such a procedure were really overwhelming. There were days in the beginning when we weren't sure we had made the right choice, but then one day **Diane Randall** appeared. Diane came into our NICU room with a big binder full of tracheostomy information and our chins hit the floor. She said that over time and with proper training we would become experts when it came to our daughter and her trach care. Sure enough, over the next several weeks, we were taught a lot of information. We practiced trach care and trach changes on a training dummy. Then, Diane had us practicing on Victoria. We learned what worked for us and for Victoria and it became easier. This huge mountain we thought we were climbing wasn't as intimidating anymore. Victoria is breathing so much better, she is growing, and she is thriving. Hopefully she won't need her tracheostomy for too long, but we'll ride this train until she's ready to get off.



#### AUS: GABBY CHESSELLS – TRACHEOSTOMY PATIENT, FAMILY MEMBER AND PROFESSIONAL

My mother was diagnosed with polychondritis in 1999. Polychondritis is a rare autoimmune disorder characterized by episodes of painful, destructive inflammation of the cartilage and other connective tissues in many organs. Most commonly it affects the

nose, eyes and trachea. Over time, my mother found it increasingly difficult to breathe, this was due to the narrowing and collapsing of her airway. In 2005 she had a permanent tracheostomy inserted at St Vincent's Hospital, Melbourne.

I was 12 years old when my mother's tracheostomy was inserted, I was away on grade 6 school camp at the time. I don't remember much about the reason why my mother had to get a tracheostomy. All I can remember is her being acutely unwell and my principal at school telling me I had to leave camp to go to Melbourne to see her (which is 2 hours away from my home).

I remember the day the speech pathologist came in to my mother's room in the hospital and explained the process of the tracheostomy using 'trache T.O.M'. Initially, I remember thinking 'gosh isn't she pretty!' and it was from this moment onwards I realised that I wanted to be a speech pathologist. I knew that I wanted to work in a position where I could help people living with a tracheostomy like my mother.

I graduated from Charles Sturt University in Albury/ Wodonga with a bachelor of speech pathology in 2014. Since then it has been my ambition to work with patients living with a tracheostomy. I was lucky enough to have in my mother, someone who I could practise on daily. However, this did not last long enough as my beautiful mother passed away on 21st May 2016.

I know that she is extremely proud of me that I am working in the field that I am. Whenever I see a tracheostomy patient, it's the first thing I tell them. To give them re-assurance that I may not know exactly what they are going through but I know what it is like to be a family member. I know what it's like to be the 12-year-old girl growing up with a mother with a tracheostomy. This is the sole reason why I signed up to be a part of the global tracheostomy collaborative so that I can share my experience and learn from the experiences of others living with a tracheostomy.



#### USA: JOHN PAUL'S TRACHEOSTOMY JOURNEY: A DECANNULATION EXPERIENCE

We have come such a long way from our 11b 12oz baby who was like a tiny bird with no feathers and a floppy "wet noodle" airway, he thus required a tracheostomy. The journey began with us spending 5 ½ month in NICU and then 5 years

of 24 hour vigilance to keep our son breathing and well. God carried me and my husband, Neal, was my faithful rock. It has been a long and intense roller-coaster ride. John Paul has made us better people and has been and is a light and inspiration to countless others. Almost every emotion that a parent can feel in the lifetime of their child was front loaded for us in the first five years of John Paul's life. The very thought of this chapter of our lives being a thing of the past brought on a tidal wave of emotions. The relief knowing that the years of doing tedious tasks, being hyper vigilant, obsessing about having enough sterile q-tips and trach ties, sterilizing anything I could, having sleepless nights, having a constant presence of nurses, not having surgeries and long hospital stays all bring tears of relief. Longing for the day I can just have mommy time freely. The only analogy I can come up with is the feeling one would have finding out a family member was in a horrific car accident, the waiting to see if they will live, followed by the profound relief of the moment you find out they are going to be ok. For so many days and nights I did not know how long I would have my son on this earth. We have survived this chapter! The trach is out so why are we not filled with anything but elation?!

A couple of unexpected turns such as the anxiety of waiting for his gaping stoma to be closed surgically because after six weeks it has not closed on its own and survivor's guilt. Survivors guilt is a deep and painful hidden emotion thinking of all of those who may never be able to live Trach free. The ones who have far greater challenges with no end in sight. The survivor's quilt is so deep because you want that same relief and hope for everyone of your fellow moms! You minimize your happiness out of love because you know if you were them it can be so painful seeing other children progress. Just like when we were in NICU for 164 days and saw babies come and get to go home. There are brief moments of hope and happiness thinking of what may now be possible: swimming, washing hair in the bathtub, living freely at home as a family, freedom from machines and carrying multiple bags. There are also feelings of losing an entire community that has



become family. Wondering if I will still fit in with all those who have become our family over the last five years.

The words of Dr. Sohit Paul Kanotra, Pediatric Otolaryngologist,

a year prior to decannulation that the LTR (laryngeal tracheal reconstructive) surgery was his only hope of getting the Trach out made my heart anxious and hopeful at the same time. I was able to move through that anxiety with my husband thanks to God and the gift of Dr. Kanotra, who had years of success with this complex surgery. The level of skill and competency coupled with the immense compassion and support from Dr. Kanotra was a guiding light amid this rollercoaster journey. He constantly encouraged us as parents, reassured us that we too were the reason John Paul was doing so well due to our care. Dr. Kanotra also took us through each option as we came to a crossroad in his care, clearly laying out all of the options. We have continually put all in God's hands every day, receiving peace and grace to carry us through maintaining our sanity and now we wait again in a state of the unknown. We were once again waiting; waiting for his last bronchial scope and waiting hearing the words that the Trach can most definitely come out. We were days away from the biggest moment of truth of our lives. Dr. Kanotra has been gifted and used by God to help us successfully navigate this journey. He has been the answer to so many prayers. We have taken steps forward even when we didn't see ground below us. Thursday August 16th was the day that began our new chapter. After our discharge from Children's Hospital of New Orleans, five years after his birth, we brought home a new "baby"! John Paul no longer gets his voice taken away every night and I can actually hear him talking in his sleep!

There is no more portable suction machine or trach go bag to carry, no more air compressor at night, no more noise at night, no more trach care or trach change, no more supplies to stock, no more hoarding supplies in case he gets sick. The first couple of weeks the silence was deafening with only a pulse oximeter. That little red light on his toe glowing in the dark gave me reassurance that all is OK in this strange new world. For the first time I got to rock my son with no machines. I sobbed as I rocked him. Something so simple that so many moms take for granted and some moms will never experience. To experience both worlds before and after having a child with a trach is a sacred gift that I will forever treasure. Because of him, I am one of the founding partners of Trach Mommas of Louisiana that another mom and I started because we knew we didn't want any other mom to walk this road alone. The knowledge I have gained with lived experience, will be my passion to walk alongside other moms and help make their journey a little bit easier. Thank you, God, John Paul, Neal, YaYa, Dr. Kanotra, Jessica, Kelli, Woman's NICU staff and the entire support system who carried us.

## NEW COMMITTEE MEMBERS INTRODUCTIONS



### TASHA BROWN

In our last GTC Patient and Family Newsletter issue, we shared that Tasha Brown was a part of our patient and family panel at the 4th International

Tracheostomy Symposium. She is mother to Tyler, who lives with a tracheostomy and partners with her son's hospital, Children's of Colorado.



JENNY MESSER AUS Parent

As Jenny shared in her article earlier in this newsletter (page 6), she is the mother to Sally, a young adult living with

a tracheostomy and has recently joined our GTC Patient and Family Committee.



#### JOHN KEMP AUS Professional

John Kemp is a Respiratory Clinical Nurse Consultant from The Royal Children's Hospital Melbourne and has joined

our Patient & Family Committee as a professional member.



## BREAKING NEWS

AUS: The Royal Children's Hospital of Melbourne, Australia, hosted their annual KATs (Kids and Tracheostomies) Party in December, 2018. Needless to say, a fun time was had by all! Santa was there with a sack full of presents, there was face painting, finger food, music, art and crafts, and all the general festive fun that only a bunch of excited kids can provide!



THE GLOBAL TRACHEOSTOMY COLLABORATIVE HOPES THAT YOU HAD A WONDERFUL HOLIDAY SEASON WITH YOUR FAMILY, FRIENDS, AND COLLEAGUES – AND WE WISH YOU A VERY HAPPY AND HEALTHY 2019!

## GTC WEBINAR SERIES

#### TALKING TRACHEOSTOMY TUBES TO FACILITATE PHONATION AMONG MECHANICALLY VENTILATED TRACHEOSTOMY PATIENTS



#### **OBJECTIVES:**

- 1. Describe the importance of speech among mechanically ventilated patients
- 2. List different modalities available to facilitate phonation among mechanically ventilated patients
- 3. Discuss the benefits of using Above Cuff Phonation using BLUSA for those who cannot tolerate cuff-deflation
- Describe the challenges in using Above Cuff Phonation using BLUSA for those who cannot tolerate cuff-deflation – UK perspective
- Describe the challenges in using Above Cuff Phonation using BLUSA for those who cannot tolerate cuff-deflation – US perspective

#### **SPEAKERS:**

Brendan McGrath, UK | Sarah Wallace, UK Therese Cole, US | David Feller-Kopman, US Amy Freeman-Sandler, Australia

GLOBAL TRACHEOSTOMY COLLABORATIVE

#### FUTURE NEWSLETTERS

Our aim is to provide updates on the GTC developments, highlight patient and family stories and share information on topics of interest.

If you have a story to share or a topic you would like considered, please submit your story on the GTC Website or via email at patientandfamilies@ globaltrach.org



#### HELP SPREAD THE WORD

#### **FOLLOW US!**

facebook.com/ globaltracheostomy collaborative

Invite your friends to like our page too! Write a status update on your page that mentions the GTC. At the end of your message type "@global tracheostomy collaborative"



Follow and Retweet us! Our handle is @ global\_gtc. Send tweets that mention us: type "@ global\_gtc" ■

#### **SPECIAL THANKS TO:**

#### **GTC PATIENT & FAMILY COMMITTEE:**

Erin Ward, Chair, Parent (USA) Suz Barghaan, Parent (USA) Tasha Brown, Parent (USA) Gabrielle Chessells, SLP, Family (AUS) John Kemp, CNC, RN (AUS) Christine Knee Chong, CNC, RN (AUS) Colin & Jenny Gray, Patient (AUS) Sue Ellan Jones, RNC, RN (AUS) Sue Ellan Jones, RNC, RN (AUS) Angela Lorio, Parent (USA) Michael McCormick, MD (USA) Kristy McMurray, CNC, RN (AUS) Jenny Messer, Parent (AUS) Jessica Michot, Parent (USA) Diane Randall, RT (USA)