The 4th International Tracheostomy Symposium was held in Dallas, Texas February 2 & 3, 2018. This international event, with a focus on improving tracheostomy patient care worldwide, was a collaborative effort of many institutions including: The Global Tracheostomy Collaborative, The University of Texas Southwestern Medical Center, Children’s Health, and TRAMS Austin Health.

There was an incredible turnout for the ITS and the highlights included an introduction to the GTC, active discussions around international tracheostomy care, interactive panels exploring excellence in tracheostomy care, a scientific session that showcased scholarly work regarding tracheostomy and patient safety, and a patient and family session highlighting the patient and family experience and approaches to engaging patients and families in quality improvement efforts.

This GTC Patient & Family Newsletter issue will highlight the many ways that patients and families were integrated throughout the 4th ITS. One of the key drivers of the GTC is “To promote patient and family centered care and engagement.” We are thrilled with the level of patient and family participation, partnership, and engagement that took place at this international symposium and have the highlights for you here!

A POEM FOR THE 4TH ITS

Natalie Westbrook, age 17, was excited to participate in the 4th International Tracheostomy Symposium. Natalie receives care at Children’s Health, Dallas, TX, and was asked to share her experience as a teenager living with a tracheostomy and ventilator. Natalie was inspired to write the following poem for the ITS as she learned more about what the ITS event was aiming to do for the tracheostomy community. We think her poem reflects very well the collaborative learning experience that the ITS provided for both medical professionals and patients and caregivers learning together!

Until one is faced with daily uncertainty, they cannot understand our life’s philosophy, here stands the tools of our survival, the 4th International Tracheostomy Symposium, experience, collaboration, knowledge, and forever in pursuit of Life, we learn from our mistakes and experiences, we learn from others and their experiences, we learn so we can Live for a better Life, this connects us though we have no control, but we are stronger for it for we are not alone in our endeavors, patients and families and healthcare professionals, together in pursuit of a better future.
We were delighted to have **Al and Nan Smith**, Philanthropists and tracheostomy patient and spouse, share a powerful keynote conversation about their journey living with a tracheostomy. Al Smith IV is CEO of AE Smith Associates, a firm he founded in 2009. In December 2006, he retired from his position as Senior Partner of Bear Wagner Specialists, a member firm of the New York Stock Exchange, after 35 successful years on Wall Street. As the great-grandson of the legendary Gov. Al Smith, he served as Chairman of Alfred E. Smith Memorial Foundation, as well as Master of Ceremonies at the annual Al Smith Dinner for the last 29 years.

Nan Smith has been involved in her community for over 30 years. A native of Chicago and a graduate of Manhattanville College, Nan was a mother of two young children when Al was diagnosed with cancer at the age of 35. Nan and Al decided to do something positive with their experience and help others in similar crisis. Together they founded Hackers for Hope. Hackers for Hope raises money for cancer research and programs to improve the quality of life for cancer patients and their families. To date, the Foundation has donated over $20 million to worthy charities including Memorial Sloan Kettering Cancer Center and Stamford Hospital.

Al and Nan spoke passionately about the challenges they encountered when setting out on Al’s journey of learning to live with a tracheostomy. They expressed how the medical system all too often functions in silos, the lack of communication between different providers, and the responsibility that falls to the patient and family to navigate the fragmented system. Al articulated this well when he referred to Nan as “his doctor”, a feeling that resonates with many primary caregivers as they take on the role of pulling all the pieces of care together. Al and Nan, having lived the journey of adapting to live with a tracheostomy, are very committed to helping to improve tracheostomy care for all and the GTC is honored to have them serve on the GTC Board of Directors.

The Smiths were interviewed at the ITS by **Elliana Kirsh, MD** Candidate at Harvard Medical School. Elliana pursued a professional career in opera prior to medical school. After observing an otolaryngologist in the operating room, she knew that the sense of personal fulfillment she felt watching a patient regain her voice was something she could commit her life to pursuing, prompting her to shift her career focus to medicine. Elliana’s academic interests have expanded beyond care of the professional voice, to that of developing pathways to enhance communication and quality of life for patients with no voice at all. She has been involved in projects increasing the incidence of early speaking valve use, as well as events with the Global Tracheostomy Collaborative. At the closing team dinner at the symposium, she had the joy of singing a duet with Al Smith IV, a magical moment encompassing both personal and professional interests.

**PATIENT SAFETY IN THE COMMUNITY**

Trach Mommas of Louisiana, Angela Lorio and Jessica Michot, along with Dr. Catherine Hart, gave an important presentation on the challenges that tracheostomy patients and their caregivers experience in communities once discharged from the hospital. Angela and Jessica shared the challenges that they and others in their state face with getting the appropriate medical supplies they need, necessary nursing coverage, and emergency care plans in place to keep our tracheostomy patients safe in the community. This amazing duo created Trach Mommas of Louisiana and have responded to a great need in their state to work to improve tracheostomy and complex care services for patients and their families. They have done some extraordinary work around developing emergency responsive plans and work with other national organizations to achieve safety for tracheostomy patients in crisis. You can visit their website [www.trachmommas.org](http://www.trachmommas.org) for more information.
“NOTHING ABOUT US WITHOUT US” PANEL DISCUSSION

The patient advocacy motto “Nothing about us without us,” speaks to the importance of partnering with patients and families in all aspects of our quality improvement initiatives. This panel highlighted efforts from four GTC member hospitals that are committed to engaging and partnering with patients and family members. Here is a brief description of four different examples of patient engagement in tracheostomy quality initiatives and program co-designing efforts.

**Boston Children’s Hospital, Boston, USA** – Dr. Karen Watters, Dr. Mark Volk, and Erin Ward (Family Champion) shared how Boston Children’s Hospital has initiated the development and distribution of universal emergency “Go Bags” to help tracheostomy patients have a standardized emergency bag they can carry at all times. The team also shared how they hold tracheostomy multidisciplinary inpatient rounds, a monthly Multi-Disciplinary Trach Team (MDT) meeting, and an outpatient multidisciplinary clinic. Erin serves as the Family Champion and attends the monthly MDT meetings to represent the patient and family voice.

**TRAMS-Austin Health, Melbourne, Australia** – Tanis Cameron, Manager of TRAMS and Senior Speech Leader, along with virtual representation from Kristy McMurray, Nurse Clinical Specialist and Jenny and Colin Gray, Patient/Family Champions and all members of the GTC Patient & Family Committee, shared many different ways patients and families are engaged in tracheostomy care initiatives at Austin Health. A major highlight has been their highly successful Patient and Family Forums that provide an opportunity for tracheostomy patients and families to gather together and discuss the challenges and successes of their lives with a tracheostomy. They honor a recipient at each forum with a “Thriving Award” to celebrate and honor patient and family achievements.

**Manchester University Hospital, Manchester, UK** – Barbara Bonvento, Lead Physiotherapist, shared the patient and family engagement work their team is doing as core members of the National Tracheostomy Safety Project (NTSP). They have administered patient and caregiver surveys soliciting their experiences in providing tracheostomy care and the patient experience. The results will help direct the team’s initiatives. They have also created powerful patient experience videos that can be viewed on the NTSP website. ([www.tracheostomy.org.uk](http://www.tracheostomy.org.uk))

**Guys and St. Thomas NHS Trust, UK** – Dr. Asit Arora, ENT, and Co-Chair of the GTC Education and Communications Committee, spoke about our GTC Patient and Family focused webinars over the past year. He shared how the webinar team collected some valuable data from pre and post webinar surveys that indicate that webinars may be a potentially successful way to educate tracheostomy teams about the importance of integrating patients and partnering with caregivers to improve care.

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**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](http://www.globaltrach.org))

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**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/patients-families-portal/share-your-pictures-stories/](http://globaltrach.org/collaborate/patients-families-portal/share-your-pictures-stories/)
Dr. Michael McCormick, Pediatric Otolaryngologist from the Medical College of Wisconsin and member of the GTC Patient & Family Committee, along with Erin Ward, GTC Board of Directors and Chair of the GTC Patient & Family Committee, presented these tips for easing the transition from hospital to home. The tips were developed collaboratively with the GTC Patient and Family Committee and the ITS patient and family presenters, and also derived from findings from their previous work with the GTC leading to the publication: Life after Tracheostomy: Patient and Family Perspectives on Teaching, Transitions, and Multidisciplinary Teams. McCormick, Ward, etc. al. (2015) Otolaryngology-Head & Neck Surgery 153(6): 914-920. https://www.ncbi.nlm.nih.gov/pubmed/26286873.

## Easing the Transition from Hospital to Home: Top 10 Tips

### Multidisciplinary Discharge Plan:
Work closely with your hospital team towards discharge and advocate for a multidisciplinary approach, with all specialists working with you or your loved one towards the same goals. Develop a team checklist for discharge.

### Trach Education:
Before discharge, be sure your care team instructs you, and any family members/caregivers that will be providing care, in trach education. Learn and practice all areas of trach care and management (suctioning, ambu bagging, assessing breathe sounds, changing trach, etc.).

### Emergency Care Protocols:
Prepare for all possible trach emergencies. Learn how to respond and ensure necessary emergency equipment is with you at all times in a Trach “Go bag.” Accidents can happen quickly so always have needed supplies close by to respond, stay calm, and use your training.

### Emergency Response Plan:
Develop a home emergency response plan with your provider should emergency response be needed. Identify and communicate with your local response team, transport team, stabilizing hospital, and preferred hospital for treatment if needed.

### Develop Home Routine:
With your medical team, develop a daily trach routine that will work in the context of your home. Remember it’s easy for medical care and treatments to take over your daily schedules, but work to develop a routine that also prioritizes daily things that you or your family member enjoy.

### Nursing/Care Supports:
Identify what care assistance services are available for you including home care nursing and/or personal care attendants. The availability and quality of these services vary and it’s important for you to know how to advocate for this assistance and manage having care providers in your home.

### Medical Equipment/DME Insurance:
Develop a system for managing, ordering, and inventorying the necessary medical supplies and equipment needed to care for yourself or loved one with a trach. Understand your insurance coverage and carefully track to ensure that you are receiving the benefits and supplies available to you.

### Connect with Others:
You are not alone. Ask your care team about opportunities to speak with other trach patients/families. Support is also available through online support resources.

### Patient Advocacy:
Advocate for yourself or your family member! Trust your instincts and gut regarding your care status, and help share your input and concerns with your medical team. Partner together to share knowledge and understanding, and work collaboratively to address problems.

### Trach Advocacy:
Get involved with tracheostomy care at your institution. Hospitals value patient input now more than ever, and you can be a key instrument of change by sharing your trach experiences and insights.
We were delighted to have many patients and family members joining us to present their personal experiences with life with a tracheostomy. Our patient and family session was facilitated by the ITS Patient & Family Committee Co-Chairs, Christa Combs, Clinical Nurse Specialist in Complex Care from Children’s Health, and Erin Ward, GTC Patient and Family Chair and Board of Directors. The Patient and Family speaking panel included the following presenters:

Natalie & Lynette Westbrook, Children’s Health, Dallas, TX – Natalie Westbrook, age 17, and her mom Lynette Westbrook gave a wonderful presentation about living with a tracheostomy and helpful suggestions that has made life a little easier along the way. Natalie is a successful high school student, in the National Honor Society, and spoke about looking forward to attending college in the near future. Natalie also spoke about the transition to adulthood and how she appreciates when her physicians address her directly and asks for her own insights and opinions on her plan of care now that she is becoming a more independent adult.

Gaylanor Davis, Children’s Health, Dallas, TX participated in the panel and shared her story of raising Gabby, her daughter with a tracheostomy. Gaylanor reflected on the challenges that can often come with complex care and the isolation that can occur for families. She shared that she was touched by the experience of being a part of the ITS panel and meeting other tracheostomy parents for the first time in her daughter’s journey with a tracheostomy. She spoke about being inspired to becoming more involved with the local tracheostomy patients in Dallas and staying connected to our patient and family community through the GTC.

Angela Lorio & Jessica Michot, of Trach Mommas of Louisiana, were also a part of our panel presentation. Angela, inspired by her son John Paul, and Jessica Michot, inspired by her sons Gabe and Michael, and in loving memory of Michael, this amazing duo created Trach Mommas of Louisiana. Together, this collaboration has responded to a great need in their state to work to improve tracheostomy and complex care services for patients and their families. Angela shared about the power of support that can come from other tracheostomy patients and family members and the importance of connecting with others. Jessica shared how supportive hospital medical teams can be in the process of considering and acquiring a tracheostomy and the importance of establishing personalized, shared goals of care with each individual patient and family. As shared above, you can read more about their great work at www.trachmommas.org.

Tasha Brown, Boulder, Colorado – Tasha joined our panel to share about her experience with raising her son Tyler, who lives with a tracheostomy. She also partners with her son’s hospital, Children’s of Colorado, who has recently joined the GTC as a member hospital. Tasha provides a parent perspective in the development of their programs and mentors others along the way. She spoke about parenting siblings as well, as Tyler has a twin sister Sydney. The experience and role of siblings an important

CONTINUED ON PAGE 6...
topic, as life with a tracheostomy with one child or individual often impacts the entire family. We were delighted that she traveled all the way from Colorado to join the ITS!

Jody Dravies, Key West, Florida – Jody offered a wonderfully candid perspective on life with a tracheostomy as an adult. Jody also attended the 3rd ITS in Baltimore and participated in the patient and family session that year offering insight into the lack of education she had received about how to vocalize with her tracheostomy after it was placed. Jody has an incredible zest for life and lives each day overcoming challenges her tracheostomy may present. She lives a very active life, is a runner as well, and we were grateful for her contributions and insights as an adult with a tracheostomy.

Jim Mullen, a retired police officer from Chicago that was shot in the line of duty serving his community, provided a wonderful video story for us to view that highlighted Jim’s incredible resilience and positive attitude that helped him overcome challenges that his injuries brought him. He shared how discovering his passion for making, branding, and selling his very own applesauce has brought on a new found joy and career in life. (www.mullenfoods.com) He also shared tracheostomy tips including how helpful the cough assist has been in his daily care. We were so appreciative of Jim’s virtual participation.

Colin and Jenny Gray, members of the Patient & Family Committee and representatives of Austin Health in Australia, participated virtually via a video of Colin’s journey with a tracheostomy. Colin is a farmer who received a tracheostomy following a farming accident. He shares his story in this inspirational video and how important it was for him to establish personal goals to strive for in his recovery. Jenny also asked to relay how challenging it is to find, maintain, and manage nursing and personal care assistants, a struggle for many of the patient and family members present for our session and as we know a universal challenge. We are grateful to Colin and Jenny’s longstanding contributions as patient champions. http://globaltrach.org/2014/10/hear-colin-grays-powerful-story/. 

Gerard Stevenson, a tracheostomy patient also from Melbourne Australia, generously sent copies of his book “Stand on the Shoulders of Giants”, to distribute to fellow tracheostomy patients. He shared the following inscription to patients in the book: “When I fell I smashed my C1/C2 vertebrae. It’s rare for anyone to survive this injury. I did so because my wife and three neighbours were CPR trained. They took turns massaging my heart. They kept the oxygen flowing to my lungs and brain. They kept this up for more than 30 minutes until the paramedics arrived. The paramedics couldn’t believe it, I was still alive. There was nothing left. Just a spark. Read this book carefully. In it you might discover my spark. It pulled me through then. It’s pulling me through now. This book comes with strings attached! The obligation is simple and light. When you finish reading this book pass it on. Give it to someone who enjoys stories about people who overcome the odds... or... Pass it on to someone who may need encouragement, whose stocks are low, whose spark needs a fan... or... Leave it to chance, if you are a believer, leave it to serendipity. Leave it where it can be picked up by the person who needs it most. Then, share your spark with me, and possibly others on my blog.”

Thank you Gerard! Learn more about Gerard’s blog at www.standonestheshouldersofgiants.com.au.

All of our patient stories focused on the challenges of tracheostomy life, the celebrated successes in their journeys, and tips for others who may experience a similar tracheostomy path. Some of the topics shared were the experiences of hospital life, the importance of partnering with the medical team and developing shared goals of care, the challenges of transitioning home, and the often complex community experience tracheostomy patients have navigating all the necessary aspects of care. Many thanks to all for sharing their experiences!
CARING FOR THE CAREGIVER

NaTasha Woodard, LCSW, from Children's Health, shared an informational session on the important topic of “Caring for the Caregiver.” This was an appreciated session for many patient and families members present who are often challenged by the extraordinary efforts one assumes as a caregiver of a loved one with a tracheostomy. NaTasha shared useful strategies for creating time for oneself and ideas for talking about the importance of self-care with others. The session was beneficial for family caregivers, patients themselves, and medical professionals working with tracheostomy patients as well.

THE VALUE OF PARTNERING WITH PATIENTS & FAMILIES

Having patients and families engaged in the ITS panels and speaking program brought the heart of caring for tracheostomy patients and their families front and center. The primary learning objective of engaging patients and family members throughout the ITS was to share patient and family perspectives with medical professionals, so that professionals can better understand the patient experience and help identify what is most meaningful to patients and families. Patients and families can partner with professional teams to identify what helps create a positive and safe tracheostomy experience. Attendees reported that there were several patient centered outcomes they would work to improve at their own institutions inspired by the patients and families participating and presenting at the ITS. These included: partnering with patients and families in quality improvement initiatives, involving them in multidisciplinary trach teams, engaging patients and families in care decision making, and including patients and families in the planning and implementation of educational materials and trainings. In learning collaboratively together, we can move forward with co-designing quality improvement initiatives and drive for patient-centered outcomes that are most meaningful to patients and families.

Thank you to all our patient & family speakers, medical professional speakers, and all ITS attendees that joined our Patient & Family sessions. A special thanks to GTC President, Dr. David Roberson, the entire GTC leadership team, the ITS leadership and conference planning teams for their ongoing and continued support of partnering with patients and families.

EMPOWERING THE VOICE OF THE PATIENT

We were delighted to have an incredible team of Speech and Language Pathologists come together to present on the importance of ‘Empowering the Voice of the Patient.’ ‘The Voice,’ meaning whatever means of communication that a patient is able to engage in, whether it be speech, the use of tracheostomy speech valves, sign language, augmentative communication, or additional strategies. Rachel Santiago of Boston Children’s Hospital, Prue Gregson of TRAMS Austin Health, and Cortney Van Slot of Children’s Health did a wonderful job sharing strategies for maximizing a patient’s ability to communicate and become active participants in their own care plan. Lauren Meglasson, a tracheostomy patient at Children’s Health, also gave an inspiring talk about how her communication device allows her to communicate more clearly with others and has helped her in her own tracheostomy journey. Thank you for encouraging participants to address communication strategies for patients with tracheostomies early in their care journey with a trach!
We are pleased to introduce our newest members to the GTC Patient & Family Committee:

Christine Knee Chong, CNC (AUS): My name is Christine Knee Chong and I am the new clinical nurse consultant for TRAMS at the Austin Hospital. I have a Bachelor of Science degree in Nursing and a post graduate certificate in critical care nursing. I am also completing my Masters in Public Health. Prior to working in TRAMS, I worked in the Austin Intensive Care Unit for 8 years and before that, in the Johannesburg General Hospital, South Africa ICU for two years. My passion has always been to provide optimal patient care and improvement of patient outcomes on an international level through multi-disciplinary involvement, a focus on the patient and family experience and a dedication to adopting evidence based practice. I believe that the GTC is the perfect vehicle to ensure all these components are achieved for patients with tracheostomies. I am extremely excited to be part of this tracheostomy global community and to see it grow from strength to strength.

Gabrielle Chessells, SLP and Family Member (AUS): Hi my name is Gabby Chessells. I live in regional Victoria, Australia. I am a speech pathologist at my local hospital and I am very passionate about tracheostomies as my mother lived with a tracheostomy for over 13 years. It was growing up with a mother living with a tracheostomy that fueled my passion to become a speech pathologist. It’s my goal to work with patients living with a tracheostomy and I think I have a unique experience to share in GTC.

VJ, Patient (UK): VJ, a childhood cancer survivor from the UK, has joined the committee. Since having a permanent tracheostomy three years ago, she has taken early medical retirement from her social work career and lives in the community with her family. She now spends her time volunteering as a breast feeding supporter and networking through social media to gain support for others with permanent tracheotomies.

Angela Lorio & Jessica Michot, Trach Mommas of Louisiana, Parents (USA): Angela and Jessica, parents and the founders of Trach Mommas of Louisiana are doing amazing work to assist families in Louisiana and beyond. You can read more about their efforts earlier in this newsletter, as we were delighted to have them present at the 4th ITS. We are happy to have them join the GTC Patient & Family Committee to continue to share their knowledge and experience in patient advocacy. They have already begun to partner with Children’s Hospital of New Orleans, a new member hospital of the GTC.

Welcome to all our new committee members and thank you to all our committee members that help to incorporate the voice of tracheostomy patients and families into all the work we do at the GTC!

SPECIAL THANKS TO:

4TH ITS LEADERSHIP TEAM:
Eric Gantwerker, MD
Rebecca Brooks MSN
Michael Brenner, MD
Emily Roman, MPAS

4TH ITS PATIENT & FAMILY COMMITTEE:
Christa Combs, Co-Chair
Erin Ward, Co-Chair
Lariba Abu
Candice Bailey
Kristy McMurray
Diane Randall
Cindy Whitney
NaTasha Woodward

GTC PATIENT & FAMILY COMMITTEE:
Erin Ward, Chair, Parent (USA)
Suz Barghaan, Parent (USA)
Gabrielle Chessells, SLP, Family (AUS)
Christine Knee Chong, CNC, RN (AUS)
Colin & Jenny Gray, Patient (AUS)
Sue Ellan Jones, RNC, RN (AUS)
Angela Lorio, Parent (USA)
Michael McCormick, MD (USA)
Kristy McMurray, CNC, RN (AUS)
Jessica Michot, Parent (USA)
Diane Randall, RT (USA)
VJ, Patient (UK)
How Can I Get Involved?

Is your health care provider a member of the GTC? If not, talk to them about joining the GTC and becoming part of a growing and exciting network of committed professionals striving to improve tracheostomy care.

By joining the GTC, your health care provider can track outcomes and work with specialists from around the world to change practices that will improve your tracheostomy experience.

BECOME A PATIENT OR FAMILY MEMBER FOR FREE!
You can register online at the GTC homepage www.globaltrach.org.

AS A MEMBER YOU WILL:
- Receive updates on GTC developments
- Learn ways you can connect with other patients and families
- Share your story for others to learn about life with a trach
- Become part this exciting movement improving tracheostomy care around the world.

WE WANT TO HEAR FROM YOU! Please email questions you may have about the GTC or ideas you have for engaging patients and families in improving tracheostomy care to patientandfamilies@globaltrach.org.

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/

UPCOMING PATIENT & FAMILY EVENTS
AUSTRALIA
- GTC Patient and Family Meeting
  AUGUST 22ND, 2018
  Austin Health
  Melbourne, AUS

FUTURE NEWSLETTER ISSUES
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 email patientandfamilies@globaltrach.org.

HELP SPREAD THE WORD
Follow us on Facebook and Twitter!

www.facebook.com/globaltracheostomycollaborative

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”

https://twitter.com/global_gtc

Follow and Retweet us! Our handle is @global_gtc. Send tweets that mention us: type “@global_gtc”