

### A LETTER FROM THE PRESIDENT OF THE GTC



Welcome to the inaugural Global Tracheostomy Collaborative (GTC) Patient & Family Newsletter. Many thanks to Erin Ward, Kristy McMurray, and the entire patient and family committee for putting this newsletter together, and for championing the role of patients and families within the GTC.

The GTC came into existence because tracheostomy experts from around the world recognized that a small number of hospitals were demonstrating excellent tracheostomy outcomes. Through teamwork, standardization, education and data collection they were able to radically reduce complications and adverse events among patients.

The goal of the GTC is to spread these practices to all hospitals that care for tracheostomy patients. We encourage hospitals to join the GTC, to implement our program, and to collect outcomes data in our worldwide confidential database.

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#### ULTIMATELY, WHAT WE CARE ABOUT THE MOST IS PATIENT OUTCOMES AND PATIENTS' EXPERIENCE

The patient and family committee is a critical component of the GTC because we rely on patients and families to make sure that what we do ultimately provides the most value to patients with their tracheostomy and their loved ones. I can't thank the committee enough for taking the time and energy to help us do the best possible job. ■

### GTC PATIENT & FAMILY COMMITTEE

The GTC Patient & Family Committee has champions from all over the world committed to working closely with patients and families to improve tracheostomy care around the globe through the GTC and promoting the patient experience.



GTC P&F Committee at the 3rd International Tracheostomy Symposium in Baltimore USA 2016.

The GTC P&F Committee is made up of Patients, Family members, Doctors, Nurses, Speech Pathologists and Physiotherapists with adult and pediatric tracheostomy experience. We have members from all over the world including USA, UK, Europe, Australasia and Canada. Our hope is to have representation from from every continent and country in the future.

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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**

We recognize incorporating the patient and family voice into tracheostomy quality improvement initiatives is essential. The GTC P&F Committee ensures the patient and family perspective is reflected throughout the entire GTC program.

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**PATIENT CENTERED CARE' IS A HEALTH CARE CULTURAL SHIFT ALL OVER THE WORLD THAT IS CHANGING HOW CARE IS DEVELOPED, DELIVERED AND IMPROVED FOR THE BETTER.**

Including the patient experience at all levels of health care from executive meetings through to direct patient to clinician feedback reminds health care professionals what matters most and helps to foster change in practice, policy and care.

As part of our commitment to improving tracheostomy care, we encourage all hospitals to enroll as GTC members with a Patient or Family Champion as a member of their multidisciplinary tracheostomy teams (MDTs). Our hope is that hospitals will engage with patients to improve safety, and create better tracheostomy care. ■

## EUROPEAN GTC MEETING OCTOBER 3RD 2016, MILAN, ITALY



European GTC kickoff, Milan, Italy was held on October 3rd, 2016 in partnership with the European Society of Intensive Care Medicine's 29th Annual Congress (ESICM).

A strong focus to the kick off was how joining the GTC, collaborating with patients and families and implementing a standardized multidisciplinary tracheostomy team model of care was an important and essential step towards improving tracheostomy outcomes globally.

As part of the European GTC kick off, the GTC Patient & Family Committee Chair, Erin Ward presented as a part of the speaking program and shared the voice of patients and families in tracheostomy care with attendees. ■

# 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](http://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](mailto:patientandfamilies@globaltrach.org). ■

# GTC KICKOFFS AND THE PATIENT & FAMILY SESSIONS

Since 2014, the GTC has been hosting 'Kickoff' events around the world to help spread the word about the GTC and its aim to improve tracheostomy care globally. Events have been held in the United States, England, Australia and most recently Milan.

The 'kickoffs' are primarily about raising awareness of the GTC and getting hospitals to participate in the GTC's exciting mission to bring health professionals, patients and families together to collaborate and create better care everywhere.



Guest Speaker Professor Steven Hawking, European GTC Kickoff July 2014, London, UK.

The idea is that kickoffs generate excitement and momentum to encourage hospitals to become members of the GTC and start the journey to improve tracheostomy care at their health care center.

At each of the kickoff events, we have had a patient and family session bringing together patients, families and health care professionals to share their stories and welcome them to join the GTC efforts.

The sessions are an integral component of the GTC meetings and provide an invaluable opportunity for health care professionals, patients and families to talk, listen and learn from each other.

Last year, GTC Kickoffs were held in Baltimore, USA and Milan, Italy. The USA Kickoff was jointly held with the *3rd International Tracheostomy Symposium at Johns Hopkins in Baltimore, Maryland, USA*. At this exciting meeting patients, families and health



Australasian GTC Kickoff Oct 8th 2014; Melbourne, Australia

care professionals all came together to develop connections, share their experiences and learn from each other.



Guest speaker O.J. Brigance and his wife Chanda, 3rd International Tracheostomy Symposium, April 2016, Maryland, USA

A highlight was hearing from inspirational US football star O.J. Brigance who lives with ALS and a tracheostomy. His story and determination to empower others was captivating and moved the entire audience.

O.J. Brigance's speech obviously got people thinking as the Patient & Family Session that followed was our largest one yet!

The session was a huge success with a room overflowing with patients, families, physicians, nurses, respiratory therapists, and speech pathologists – our own MDT audience!

There were presentations from health care professionals and parents of kids with tracheostomies.

Patients and family members in the audience also participated in the interactive discussions sharing their perspectives, giving examples of the importance of advocating for their own or a loved one's needs, emphasizing communication between healthcare providers and patients/families.

Medical professionals also shared their experiences of partnering with patients and family members in quality improvement initiatives and how their voices can serve as a driving force to positive changes in global tracheostomy care.

It was certainly impressive to see so many people in one room so dedicated and enthusiastic to work together and make a difference.

While every story and experience was unique many people could relate. By sharing their experiences of living with or caring for a tracheostomy individuals did not feel so isolated.

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Audience and speakers' stories of challenges and triumphs generated in depth discussion and made us want to learn from each other as we strive for better care.



Patient and Family Session, 3rd International Tracheostomy Symposium, April 2016, Baltimore USA.

With audience members from across the globe including Australia, Europe, and the USA it was evident that no matter where in the world you lived or worked, tracheostomy care was better if it was:

- Co-ordinated
- Standardized
- Based on best practices
- Provided by a multidisciplinary team

Exactly what the GTC is trying to achieve!

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**A PATIENT SHOULD BE ABLE TO EXPECT CARE THAT IS SAFE, COORDINATED, STANDARDIZED AND BASED ON THE BEST AVAILABLE EVIDENCE.**

In the meeting, we discussed how the GTC is helping health care institutions improve their practices. GTC member hospitals can share and compare tracheostomy outcomes to identify areas of good care and areas where they could improve.

The process of comparing outcomes is called 'benchmarking' and helps to ensure that no matter if care is received in a small town in the USA, or a large city in the UK the care should be the same.

Becoming a GTC member (free to patients and families) also provides access to resources and updates of upcoming meetings. To ensure the GTC can continue the important work, we need as many hospitals to sign up to the GTC and become GTC Members as possible. ■



## SPREAD THE WORD: RESOURCES, EDUCATION AND UPDATES

Your very own Chair of the GTC Patient & Family Committee, Erin Ward whose son lives with a tracheostomy, and fellow committee member Dr. Michael McCormick, are co-authors on a research paper 'Life after Tracheostomy: Patient and Family Perspectives on Teaching, Transitions, and Multidisciplinary Teams'.

The information to guide this paper was obtained from surveys distributed to social media support groups for tracheostomy patients and families including: [www.Tracheostomy.com](http://www.Tracheostomy.com), Moms of Trach Babies, TrachCare, and Neckbreathers' Connection.

Patients and families responded to questions regarding their experience going home with a tracheostomy.

You can access the article free via PUBMED:

***Life after Tracheostomy: Patient and Family Perspectives on Teaching, Transitions, and Multidisciplinary Teams.*** McCormick, Ward et al. (2015) Otolaryngology-Head & Neck Surgery 153(6): 914-920 917p. <https://www.ncbi.nlm.nih.gov/pubmed/26286873> ■



# HELLO FROM AUSTRALIA!

Gerard and Colin are members of the GTC and both have a tracheostomy following a spinal cord injury. They are passionate about improving tracheostomy care. They each share their story to remind us never to give up, to communicate, collaborate and never stop learning or striving for a better life and the best tracheostomy experience.

By sharing their story, they ensure the patient voice is not forgotten. They make us stop, listen and think. They inspire people to work together to achieve greatness.

### Gerard's Blog: Stand on the Shoulders of Giants.

Whether he makes you laugh, cry or simply reflect, Gerard's blog is a candidly honest account of the day to day challenges, successes and antics of living with a tracheostomy and spinal cord injury.

Visit Gerard's blog and sign up to his mailing list to get updates on his journey

[www.standontheshouldersofgiants.com.au](http://www.standontheshouldersofgiants.com.au)

### Colin's video: Thriving in the Community with a Tracheostomy.

Colin tells his emotional story from the beginning of his accident through to the time he leaves hospital. He recalls the very personal decision to keep the tracheostomy in order to leave hospital and transition back into his community. Colin's story is about never giving up and how a multidisciplinary team is essential to tracheostomy care.

At the end of the film Colin talks about his determination to do something – which since making the film he has! Check out the video on the GTC Website to find out what it is! [www.globaltrach.org](http://www.globaltrach.org). ■



Gerard with his family.



Colin with his daughter on her wedding day.

## UPCOMING PATIENT AND FAMILY EVENTS

### AUSTRALIA

- GTC Patient and Family Meeting - Joining forces, leading change and improving lives  
**APRIL 4TH 2017**, Hosted by Austin Health, Melbourne Australia

### EUROPE

- No events currently scheduled

### USA

- Global Tracheostomy Tube Awareness Week- hosted by Moms of Trach Babies, **THIRD WEEK IN MAY (5/14-5/20)** online event at <https://www.facebook.com/GlobalTracheostomyTubeAwareness/?fref=ts> ■

## 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](mailto:patientandfamilies@globaltrach.org) ■



## GTC PATIENT AND FAMILY COMMITTEE

We also would like to acknowledge the following members of the committee who volunteer their time working together to help the GTC make a difference in the lives of tracheostomy patients.

- Erin Ward, Parent (USA)
- Kristy McMurray, CNC, RN (AUS)
- Michael McCormick, MD (USA)
- Suz Barghaan, Parent (USA)
- Jackie Mcrae, SLT (UK)
- Sue-Ellen Jones, RNC, RN (AUS)
- Colin & Jenny Gray, Patient (AUS)
- Kevin Callans, BSN, RN (USA)
- Matthew Stewart, MD (USA)
- Nina Desell, RN (USA)
- Haley Rayburn (USA)
- Christine Milano (USA) ■