

2017 ABTA PATIENT AND FAMILY CONFERENCE PROGRAM
Redefining Survivorship through Science, Technology and Clinical Innovation
August 4-5, 2017 (Friday-Saturday)
The Westin O'Hare, 6100 North River Road, Rosemont, Illinois

Program Co-Chairs:

[Elizabeth B. Claus, MD, PhD](#), Department of Neurosurgery, Brigham and Women's Hospital, Boston, MA and the Yale School of Public Health, New Haven, CT

[Jeffrey S. Wefel, PhD](#), Associate Professor and Section Chief, Department of Neuro-Oncology, The University of Texas MD Anderson Cancer Center, Houston, TX

Friday, August 4

* Friday registration and check in takes place at 8:00 a.m. and will close at 4:00 p.m. Registration is located in the Foyer between Higgins and the Front Desk of the Westin O'Hare.

8:00 a.m. – 4:00 p.m. **Registration and Check-In** Foyer

8:00 a.m. – 5:00 p.m. **ABTA Patient and Caregiver Lounge** Michigan A

8:00 a.m. – 9:00 a.m. **Continental Breakfast** LaSalle Ballroom / Foyer

8:45 a.m. – 9:45 a.m. **Brainlab Focus Group: Living with Brain** Dearborn

Metastases: What are my Options?

[Jocelyn Mohr, MBA](#), Patient Marketing Manager, Brainlab, Inc.

As new treatment options for primary cancer enable patients to live longer, incidents of brain metastases are on the rise. With interviews and animations, this film covers topics from the basics of the disease to various traditional and advanced treatment options and their potential side effects. The film features ten clinicians and the CEO of the American Brain Tumor Association and is framed through the story of a brave patient with multiple brain metastases who continues to thrive in spite of her diagnosis.

9:00 a.m. – 9:45 a.m. **Empowerment: What Brain Tumor Patients Need to Know** Division

[Daniel H. Lachance, MD](#), Clinical Neuro-Oncologist, Section of Neuro-Oncology, Mayo Clinic.

This session covers how to navigate the early days of a brain tumor diagnosis and what information patients, families, and caregivers would need to know in order to be empowered with information and resources to make informed decisions through their treatment and care.

Opening Session Part I LaSalle Ballroom

10:00 a.m. – 10:15 a.m.

Welcome

Elizabeth M. Wilson, ABTA President and CEO

10:15 a.m. – 12:00 p.m.

Panel: Science and Survivorship

Moderator: [Elizabeth B. Claus, MD, PhD](#), Department of Neurosurgery, Brigham and Women's Hospital, Boston, MA and the Yale School of Public Health,



New Haven, CT

- Panelist Presentations**
- 10:15 a.m. – 10:45 a.m. **Neurocognitive Function in Patients with Brain Tumors**
[Jeffrey S. Wefel, PhD](#), Associate Professor and Section Chief, Department of Neuro-Oncology, The University of Texas MD Anderson Cancer Center, Houston, TX
This session will describe cognitive effects of cancer and cancer treatment, classic intervention approaches to compensate for cognitive deficits, and innovative research that may lead to therapies to prevent impairments and restore function.
- 10:45 a.m. – 11:15 a.m. **Discovering New Genes for Glioma**
[Melissa L. Bondy, PhD](#), Professor of Epidemiology and Population Sciences, Baylor College of Medicine
This session will describe risk factors have been associated with glioma includes genes that have been discovered through epidemiologic studies.
- 11:15 a.m. – 11:45 a.m. **Novel Designs for Brain Tumor Clinical Trials**
[Brian Alexander, MD](#), Disease Center Leader, Radiation Oncology, Center for Neuro Oncology, Dana-Farber Cancer Institute
This session will describe traditional and newer clinical trial designs that will hopefully reduce the time required to identify treatments that work.
- 11:45 a.m. – 12:00 p.m. **Open Speaker Panel with Audience Questions**
- 12:00 p.m. – 12:45 p.m. **Lunch, Networking & Exhibit Visits** LaSalle Ballroom
- Opening Session Part II** LaSalle Ballroom
- 1:00 p.m. – 2:45 p.m. **Panel: Technology, Clinical Innovations & Survivorship**
Moderator: [Jeffrey S. Wefel, PhD](#), Associate Professor and Section Chief, Department of Neuro-Oncology, The University of Texas MD Anderson Cancer Center, Houston, TX
- Panelist Presentations**
- 1:00 p.m. – 1:30 p.m. **What is the Optimal Surgery for Glioma?**
[Daniel P. Cahill, MD, PhD](#), Associate Professor of Neurosurgery, Harvard/Massachusetts General Hospital
This session will describe the recent World Health Organization re-classification of glioma and the extent to which these data re-define the selection of surgical treatment for glioma patients.
- 1:30 p.m. – 2:00 p.m. **How does Image-Guided Surgery Improve Patient Outcome?**
[Alexandra J. Golby, MD](#), Professor of Neurosurgery, Harvard Medical School, Brigham and Women's Hospital



This session will describe new technologies in image-guided neurosurgery including the use of intra-operative MRI, ultrasound and laser to treat patients with brain tumors.

2:00 p.m. – 2:30 p.m.

Radiation vs. Stereotactic

[Jing Li, MD](#), Assistant Professor Department of Radiation Oncology, MD Anderson Cancer Center

This session will cover the relative risks and benefits of Whole-Brain Radiation Therapy (WBRT) versus Stereotactic Radiation for patients with brain tumors.

2:30 p.m. – 2:45 p.m.

Open Speaker Panel with Audience Questions

2:45 p.m. – 3:00 p.m.

Break & Exhibit Visits

LaSalle Ballroom

3:00 p.m. – 4:15 p.m.

Panel: Targeted Therapies

LaSalle Ballroom

Moderator: [Elizabeth B. Claus, MD, PhD](#), Department of Neurosurgery, Brigham and Women's Hospital, Boston, MA and the Yale School of Public Health, New Haven, CT

Panelist Presentations

3:00 p.m. – 3:30 p.m.

Meningioma and Brain Metastases

[Priscilla Brastianos, MD](#), Director, Central Nervous System Metastasis Program, Massachusetts General Hospital/ Harvard Medical School

This session will highlight the novel ways in which the discovery of tumor genetic variation is allowing for targeted therapy of both meningioma and brain metastases.

3:30 p.m. – 4:00 p.m.

Therapeutic Advances in the Treatment of Glioma

[Ryan T. Merrell, MD](#), Director of the Neuro-Oncology Program at NorthShore Neurological Institute, NorthShore University HealthSystem

This session will provide an update on treatments for glioma, including the use of immunotherapy

4:00 p.m. – 4:15 p.m.

Open Speaker Panel with Audience Questions

4:15 p.m. – 4:20 p.m.

Closing Comments: Co-Chairs

[Elizabeth B. Claus, MD, PhD](#), Department of Neurosurgery, Brigham and Women's Hospital, Boston, MA, and the Yale School of Public Health, New Haven, CT

[Jeffrey S. Wefel, PhD](#), Associate Professor and Section Chief, Department of Neuro-Oncology, The University of Texas MD Anderson Cancer Center, Houston, TX



4:20 p.m. – 4:30 p.m.	<p>Research Poster Session Overview</p> <p>Anita Hjelmeland PhD, Assistant Professor, Department of Cell, Developmental and Integrative Biology, University of Alabama at Birmingham, and ABTA Alumni Research Network Annual Meeting Co-chair</p>	
4:00 p.m. – 4:50 p.m.	<p>Brainlab Focus Group: Living with Brain Metastases: What are my Options?</p> <p>Jocelyn Mohr, MBA, Patient Marketing Manager, Brainlab, Inc. As new treatment options for primary cancer enable patients to live longer, incidents of brain metastases are on the rise. With interviews and animations, this film covers topics from the basics of the disease to various traditional and advanced treatment options and their potential side effects. The film features ten clinicians and the CEO of the American Brain Tumor Association and is framed through the story of a brave patient with multiple brain metastases who continues to thrive in spite of her diagnosis.</p>	Dearborn
4:30 p.m. – 4:45 p.m.	Break & Exhibit Visits	LaSalle Foyer
4:30 p.m. – 5:15 p.m.	Meet the Researchers: Researcher Poster Viewing Session	LaSalle Foyer
6:00 p.m. – 8:00 p.m.	Dinner	LaSalle Ballroom
6:15 p.m. – 6:45 p.m.	<p>2017 Joel A. Gingras, Jr. Award Presentation</p> <p>Carol Kruchko, President and Founder, CBTRUS</p>	
7:00 p.m. – 7:30 p.m.	<p><u>Keynote Speaker</u></p> <p>Disappointments, Progress and Promises in the Treatment of GBM</p> <p>Roger Stupp, MD, Co-Director, Northwestern Brain Tumor Institute, Northwestern University and Northwestern Medicine</p>	LaSalle Ballroom



Saturday, August 5

* Saturday registration and check-in takes place at 7:30 a.m. and will close at 1:30 p.m. Registration is located in the Foyer between Higgins and the front desk of The Westin O'Hare.

* For those of you who have chosen to be overnight guests at The Westin O'Hare, please check your luggage between the hours of 7:30 a.m. – 2:00 p.m. at the office across Division.

7:30 a.m. – 2:00 p.m. **Registration and Check-In** Foyer

7:30 a.m. – 3:00 p.m. **ABTA Patient and Caregiver Lounge** Michigan A

7:30 a.m. – 8:30 a.m. **Continental Breakfast** LaSalle Ballroom / Foyer

7:30 a.m. – 2:00 p.m. **Exhibit Visits** LaSalle Foyer

9:00 a.m. – 9:15 a.m. **Welcome** LaSalle Ballroom
Elizabeth M. Wilson, ABTA President and CEO

9:15 a.m. – 11:00 a.m. **Panel: Engaging Patients in Research** LaSalle Ballroom
Moderator: [Jeffrey S. Wefel, PhD](#), Associate Professor and Section Chief, Department of Neuro-Oncology, The University of Texas MD Anderson Cancer Center, Houston, TX

Panelist Presentations:

9:15 a.m. – 9:45 a.m. **Computerized Cognitive Training: Brain Games & Brain Training**
[Heather Conklin, PhD](#), Pediatric Neuropsychologist/Associate Faculty Member, St Jude Children's Hospital
This session will describe and discuss the use of computerized brain training to treat disorders of cognitive function.

9:45 a.m. – 10:15 a.m. **Engaging Patients in Research: The International Low Grade Glioma Registry**
[Elizabeth B. Claus, MD, PhD](#), Department of Neurosurgery, Brigham and Women's Hospital, Boston, MA and the Yale School of Public Health, New Haven, CT
This session will introduce the International Low Grade Glioma (LGG) Registry, a novel web-based partnership with the ABTA and NBTS being undertaken to study LGG.

10:15 a.m. – 10:45 a.m. **Meningiomas and Fatigue**
[Gelareh Zadeh, MD, PhD, FRCSC](#), Clinician Scientist, Head of the Division of Surgical Oncology, Princess Margaret Cancer Centre, University Health Network
Dr. Zadeh will present some of the results of a survey of meningioma patients and discuss areas in need of research based on these results. She will talk about



how we can integrate patients' perspectives and needs into quality and research design. This session will also discuss the pathophysiology, presentation, and management of fatigue in patients with meningiomas.

- 10:45 a.m. – 11:00 a.m. **Open Speaker Panel with Audience Questions**
- 11:00 a.m. – 11:15 a.m. **Break & Exhibit Visits** LaSalle Foyer
- 11:15 a.m. – 12:00 p.m. **Break-out Session I (choose one)** Lobby Level

Altering Metabolism for Brain Tumor Therapy: Food for Thought Madison

[Adrienne Scheck, PhD](#), Associate Professor, Barrow Neurological Institute

[Leonora Renda, MS, RDN](#), Manager of Nutritional Services, Dignity Health

This session will describe our current understanding of the role of diet in health and disease including defining a ketogenic diet and how to implement it.

Improve Quality of Life for the Caregiver Dearborn

[Margaretta S. Page, RN, MS](#), Nurse Coordinator UCSF Neuro Oncology Gordon Murray Caregiver Program, UCSF Neuro-Oncology

This session will discuss common issues that caregivers face and strategies for caregivers to help themselves and their loved ones with brain tumors.

Depression & Mood Swings Division

[Debra Kangisser PA-C](#), Physician Assistant, Cleveland Clinic

This session will discuss mood and behavioral changes experienced by patients with brain tumor as well as pharmacologic and behavioral management strategies.

Brain Tumor in Adults & Rehabilitation Michigan B

[Rajesh R. Yadav, MD](#), Associate Professor, Section of Physical Medicine and Rehabilitation University of Texas M.D. Anderson Cancer Center

Cancer and the various treatments used to control or cure the disease frequently can affect survivors' ability to function. However, throughout the continuum of care, it is important to not only improve survival but keep a focus on function.



12:00 p.m. – 12:45 p.m. **Lunch & Exhibit Visits** LaSalle Ballroom / Foyer

1:00 p.m. – 1:45 p.m. **Break-out Session II (choose one)** Lobby Level

Supportive Care and Brain Tumors Madison

[Tobias Walbert MD PhD MPH](#), Co-Director Hermelin Brain Tumor Center Henry Ford, Henry Ford Health Systems Detroit

This session will focus on the role of supportive care, symptom management and how patients and their loved ones might benefit from advance care planning to reduce anxiety and other psychological stress factors caused by uncertainty.

Epilepsy Management in Neuro-Oncology Dearborn

[Rimas Lukas, MD](#), Associate Co-Chief, Division of Neuro-Oncology, Northwestern University

This session will discuss epilepsy management and the associated quality of life issues including drug-related symptoms, restrictions on driving, and return to work.

The International Low Grade Glioma Registry: Information Session and Enrollment Opportunity Division

[Elizabeth B. Claus, MD, PhD](#), Department of Neurosurgery, Brigham and Women's Hospital, Boston, MA and the Yale School of Public Health, New Haven, CT

The purpose of this registry is to discover why some people develop LGG while other people do not. The goal is also to learn more about the effect of this diagnosis and the associated treatments on daily life including the ability to work, drive, sleep, exercise, or take care of oneself and/or family.

Treatment of Tinnitus & Hearing Loss in Patients with Acoustic Neuromas Michigan B

[Ravi N. Samy, MD, FACS](#), Chief of the Division of Otology/Neurology at The University of Cincinnati College of Medicine

This session will discuss hearing loss associated with acoustic neuromas.

1:45 p.m. – 2:00 p.m. **Break & Final Exhibit Visit** LaSalle Foyer

2:00 p.m. – 3:00 p.m. **Panel: Living Well With a Brain Tumor** LaSalle Ballroom

Moderator: [Elizabeth B. Claus, MD, PhD](#), Department of Neurosurgery, Brigham and Women's Hospital, Boston, MA and the Yale School of Public Health, New Haven, CT



	<u>Panelist Presentations</u>	LaSalle Ballroom
	Getting a Perspective: Patient, Caregiver & Health Care Professional	
	Martin Romero, a five year GBM survivor and caregiver Karma Punwasi share their story about living with a brain tumor diagnosis. Dr. Jay-Jiguang Zhu shares his experience in treating Martin.	
2:00 p.m. – 2:15 p.m.	Patient Perspective	
	Martin Romero , Five-year GBM survivor	
2:15 p.m. – 2:30 p.m.	Caregiver Perspective	
	Karma Punwasi , Caregiver to husband	
2:30 p.m. – 2:45 p.m.	Health Care Professional Perspective	
	Jay-Jiguang Zhu, MD, PhD , Director of Neuro-oncology and Associate Professor, Mischer Neuroscience Associates and Department of Neurosurgery, University of Texas Health Science Center in Houston, UTHealth and Memorial Hermann	
2:45 p.m. – 3:00 p.m.	Open Speaker Panel with Audience Questions	
3:00 p.m. – 3:30 p.m.	<u>Closing Session</u>	LaSalle Ballroom
	Gerardo and Mary Ellen's Journey with GBM	
	Kyle Holen , AbbVie Executive Medical Director, Oncology Clinical Development	
	On April 15, 2016, Gerardo was diagnosed with glioblastoma, the most common and deadly malignant primary brain tumor in adults. Since then, he has bravely fought the disease with the constant support of his wife of 20 years, Mary Ellen, and the encouragement of his children. Through the American Brain Tumor Association, Gerardo and Mary Ellen found helpful information, as well as other patients and families impacted by brain tumors. Today, Gerardo is getting back to hobbies, like creative writing, and making the most of every day with his family. Working with AbbVie, Gerardo and Mary Ellen are sharing their experience with GBM in hopes of providing guidance and inspiration to other families going through a similar journey.	
3:30 p.m.	Closing Comments & Adjourn	LaSalle Ballroom

