One Retinoblastoma World

Washington DC ☆ October 9-11, 2017

Hosted by World Eye Cancer Hope

Program

Monday, October 9, 2017

Survivor and Family Day Programming

Potomac Rooms D, E and F (unless otherwise indicated)

7:45 – 8:15 am: Continental Breakfast & Networking

8:15 – 9:00 am: Welcome Remarks and Introductions

Session Leader:

- Marissa D. Gonzalez, President and Founding Board Member, World Eye Cancer Hope USA; Event Chair, One Retinoblastoma World 2017; Retinoblastoma Survivor.

9:00 – 9:50 am: Motivational Monday Morning

Session Leader:

- Bruce Van Horn, Motivational Speaker and Life Coach.

Session Topics:

- Retinoblastoma and living to your fullest potential
- Empowering yourself and others
- Creating a clear and balanced plan for your future

10:00 – 10:50 am: Breakout Sessions – Ask A Survivor

SESSION ONE: Ask a Survivor – Parents and Families

Session Topic: An open Q&A for parents and caregivers with adult survivors. A safe place to seek guidance on any topic relating to retinoblastoma, from treatment to survivorship.

Session Leaders:

- Len F. Burns, M.A., Licensed Marriage and Family Therapist, Santa Cruz, California; Retinoblastoma Survivor.
- Katherine Derganc-Billings, Retinoblastoma Survivor; Parent of Retinoblastoma Survivor Lucia Billings, Age 2.

SESSION TWO: Ask a Survivor – The Younger Generation

Location*: Chesapeake Room

Session Topic: An open Q&A for teenagers with adult survivors. A safe place to ask any question – driving, dating, self-esteem – no topic is off limits!

Session Leaders:

- Marissa D. Gonzalez (see above for title).
- Melissa Mills, M.S., CGC, LGC, Genetic Counselor, Lucile Packard Children's Hospital Stanford, Palo Alto, California; Retinoblastoma Survivor.

11:00 – 11:50 am: Parent Panel

Session Leaders:

- Mark Billings, Chief Financial Officer, World Eye Cancer Hope USA; Parent of Retinoblastoma Survivor Lucia Billings, Age 2.
- Marty Gonzalez, Parent of Retinoblastoma Survivor Marissa Gonzalez, Age 37.
- Thomas Reid, Vice President, World Eye Cancer Hope USA; Retinoblastoma Survivor; Parent of Retinoblastoma

Survivor Riana Reid, Age 20.

Session Topics:

- Caring for a child with retinoblastoma
- Family systems – maintaining healthy relationships during treatment
- Parental and family self-care
- Financial planning for a child with cancer and beyond

12:00 – 1:15 pm: Lunch Session – Survivorship and Self Care for Rb Survivors and Parents

Session Leaders:

- David R. Freyer, D.O., M.S., Director, Survivorship & Supportive Care Program, Children's Center for Cancer and Blood Diseases, Children's Hospital Los Angeles; Professor of Clinical Pediatrics and Medicine, Keck School of Medicine of USC, Los Angeles.
- Morgan Livingstone, CCLS, Certified Child Life Specialist, Toronto, Canada; Child Life Director, World Eye Cancer Hope.
- Sandra Staffieri, Retinoblastoma Care Coordinator, Royal Children's Hospital, Victoria, Australia; Clinical and Research Orthoptist, Centre for Eye Research Australia, University of Melbourne, Australia.

Session Topics:

- What is Survivorship?
- Taking Control of Your Healthcare Needs
- Balancing Emotional and Physical Stress
- Comforting Your Child During Treatment

1:30 – 2:25 pm: Genetics and Retinoblastoma

Session Leaders:

- Helen Dimaras, Ph.D., Scientist, The Hospital for Sick Children (SickKids), Toronto, Canada; Assistant Professor, The University of Toronto, Canada; Scientific Director, World Eye Cancer Hope.
- Melissa Mills (see above for title).

Session Topics:

- Second primary cancer risks
- Family planning – what do I need to know before starting a family?
- Genetic counseling services

2:45 – 6:15 pm: Washington D.C. Sightseeing Tour

Join us for a FUN and interactive private bus tour through the nation's capital. This one-of-a-kind Family and Survivor Day Tour will include stops and photo ops at various points of interest, ending with a celebratory reception at the hotel. You'll be sure to leave with a smile on your face, new friendships and connections with people from all over the world through the common bond of retinoblastoma.

6:45 – 8:45 pm: Welcome Reception

Location*: Bell20 – An American Tavern inside the Crystal City Marriott

A joyful reception shared with families, survivors and medical professionals joining us for the evening from around the world. The reception includes heavy appetizers and non-alcoholic drinks. Additional entrees and alcoholic beverages may be purchased at the venue.

CHILDREN'S PROGRAMMING

Children's Programming will take place in the Lincoln Room. It will be run by Morgan Livingstone, CCLS, Certified Child Life Specialist, and Child Life Director for World Eye Cancer Hope, and her assistant Kim Zink, Child Life Specialist.

Program

Tuesday, October 10, 2017

Potomac Rooms D, E and F (unless otherwise indicated)

7:00 – 8:05 am: Continental Breakfast & Networking

8:10 – 8:20 am: Welcome Remarks and Introductions

Session Leaders:

- Jesse L. Berry, M.D., Scientific Program Chair, One Retinoblastoma World 2017; Associate Director of Ocular Oncology-Children's Hospital Los Angeles; Assistant Professor of Opthamology, USC Roski Eye Institute, Los Angeles, California.
- Marissa D. Gonzalez, President and Founding Board Member, World Eye Cancer Hope USA; Event Chair, One Retinoblastoma World 2017; Retinoblastoma Survivor.

8:20 – 9:15 am: Awareness and Screening for Retinoblastoma

Session Leader:

- Sandra Staffieri, Retinoblastoma Care Coordinator, Royal Children's Hospital, Victoria, Australia; Clinical and Research Orthoptist, Centre for Eye Research Australia, University of Melbourne, Australia.

Session Participants:

- Katherine Paton, M.D., FRCSC, Clinical Professor of Ophthalmology, The University of British Colombia, Vancouver General Hospital; British Colombia Children's Hospital, Vancouver, Canada; Head, Ocular Oncology & Director of Diagnostic Ophthalmic Ultrasound Imaging, University of British Columbia, Vancouver, Canada.
- Michael Sullivan, Paediatric Oncologist, Clinical Lead Solid Tumors and Neuro-oncology, Royal Children's Hospital, Victoria, Australia; Continental President (Oceania), International Society of Paediatric Oncology – Paedeatric Oncology in Developing Countries (SIOP-PODC), Geneva, Switzerland.
- Ligia Fu, M.D., Pediatric Hematologist & Oncologist, Hospital Escuela Universitario, Tegucigalpa, Honduras.

Discussion Questions:

- What can we do as a group to support each other with awareness campaigns?
- What works best where?
- What does the evidence tell us?

9:20 – 10:15 am: Genetics

Session Leader:

- Brenda Gallie, M.D., Retinoblastoma Program Director, The Hospital for Sick Children (SickKids), Toronto, Canada; Professor, The University of Toronto, Toronto, Canada; Co-founder, World Eye Cancer Hope.

Session Participants:

- Melissa Mills, M.S., CGC, LGC, Genetic Counselor, Lucile Packard Children's Hospital Stanford, Palo Alto, California; Retinoblastoma Survivor.
- Hilary Racher, Ph.D., FCCMG, DABMGG, Scientific and Laboratory Director,

Impact Genetics, Toronto, Canada; Lecturer, University of Toronto, Canada.

Session Topics:

- What do genetics results mean for risk and screening, current treatment, EUA's after treatment, and for adult life?
- What if we can't access genetic testing?

10:15 – 10:30 am: Coffee Break

10:30 – 11:25 am: Enucleation

Session Leaders:

- Jonathan Kim, M.D., Director of Retinoblastoma Program, Children's Hospital Los Angeles; Associate Professor of Clinical Ophthalmology, USC Roski Eye Institute, Los Angeles, California.
- Stephen Haddad, B.C.O., B.A.D.O., Director, Ocular Prosthetics, Inc., Los Angeles, California.

Session Participants:

- Greg Dootz, A.A.S., Ocularist, Kellogg Eye Center, University of Michigan Hospital, Ann Arbor, Michigan.
- Brenda Gallie, M.D. (see above for title).

Session Topics:

- How do doctors know when trying to save an eye is dangerous, and removing it is the only option?
- How and when do we fix socket issues such as drooping eyelid, radiation damage, implant replacement etc.
- How do we best care for the socket throughout life?

11:30 – 12:25 pm: High-Risk Features in Retinoblastoma

Session Leader:

- Patricia Chevez-Barrios, M.D., Ophthalmic Pathology Houston Methodist Hospital – Retinoblastoma Center of Houston, Houston, Texas; Adjunct Professor, Department of Ophthalmology, Baylor College of Medicine, Houston, Texas.

Session Participants:

- Dan Gombos, M.D., Ocular Oncologist, MD Anderson Cancer Center/Texas Children's Hospital – Retinoblastoma Center of Houston, Texas; Clinical Co-Director, Retinoblastoma Center of Houston, Texas.
- François Doz, M.D., Professor of Paediatric Oncology & Medical Director of Training, Institut Curie, Paris, France; Professor of Paediatrics, University Paris Descartes, Paris, France.
- Murali Chintagumpala, M.D., Co-Director, Brain Tumor Program; Director, Solid Tumor Program; Co-Director, Retinoblastoma ProgramTexas Children's Hospital – Retinoblastoma Center of Houston, Texas; Professor, Baylor College of Medicine, Houston, Texas.

Discussion Question:

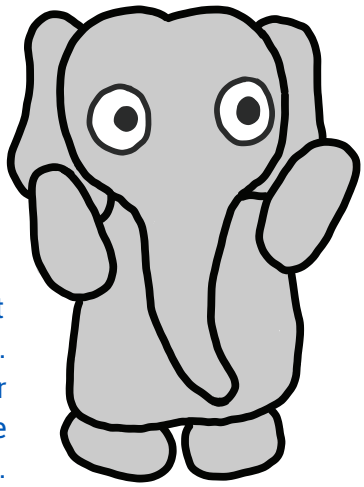
- How do doctors and parents make the decision about adjuvant chemo?

12:30 – 1:45 pm: Lunch

Location*: Chesapeake Salons B and C

Hello! My Name is Elli. Will you be my friend?

She helps children adapt to having an artificial eye. Elli may be available free-of-charge – learn more at kinderaugenkrebsstiftung.de. Plus, be sure to follow her advertures at the conference at #ElliOneRBWorld.



Program

1:50 – 2:45 pm: Retinoblastoma in Developing Countries

Session Leader:

- Lorna Renner, M.D., Associate Professor, Department of Child Health, University of Ghana School of Medicine, Accra, Ghana; Head of Paediaric Oncology Unit, Korle Bu Teaching Hospital, Accra, Ghana.

Session Participants:

- Carlos Rodriguez-Galindo, M.D., Chair, Department of Global Pediatric Medicine; Executive Vice President & Faculty Member, St. Jude's Children's Research Hospital, Memphis, Tennessee.
- Arun Singh, M.D., Director of Department of Ophthalmic Oncology, Cole Eye Institute at Cleveland Clinic, Cleveland, Ohio.
- Luiz F. Teixeira, M.D., Ophthamologist, GRAACC, San Paolo, Brazil.

Session Topics:

- What is the status of Rb in developing countries?
- I've been contacted by a family in a developing country whose child has Rb. What can I do to help them?

2:50 – 3:45 pm: Adult Survivors

Session Leader:

- Dan Gombos, M.D. (see above for title).

Session Participants:

- Katherine Paton, M.D. (see above for title).
- David R. Freyer, D.O., M.S., Director, Survivorship & Supportive Care Program, Children's Center for Cancer and Blood Diseases, Children's Hospital Los Angeles; Professor of Clinical Pediatrics and Medicine, Keck School of Medicine of USC, Los Angeles, California.
- Ruth Kleinerman, M.P.H., Ph.D., Epidemiologist, National Cancer Institute, NIH, Rockville, Maryland; Deputy Branch Chief, Radiation Epidemiology Branch, NCI, NIH, Rockville, Maryland.

Session Topics:

- What recommendations do you have for long term follow-up care and screening in RB1 mutation carriers and children treated with chemotherapy or radiotherapy?
- How can you help us educate our primary doctors so they take us seriously, and what can we do if we have no access to a survivor follow-up program?

For the following breakout sessions, delegates are invited to join one of six discussion groups. Refreshments provided.

3:45 – 4:15 pm: Breakout Sessions Treatment

Location*: Chesapeake Salons B and C

Treatment Topics (please select one of the topics to attend):

- Informed Consent
- Toxicity
- MRI Findings
- Engaging Parents
- Technologies to Advance Care
- Understanding Past Treatment

4:15 – 4:45 pm: Breakout Sessions Beyond Treatment

Location*: Chesapeake Salons B and C

Beyond Treatment Topics (please select one of the topics to attend):

- EUA Schedule
- Psychosocial Wellbeing

- PTSD in Rb Survivors, Parents, Siblings and Caregivers
- Survivor Care
- Guidance for Physicians
- Data Collection

4:45 – 5:00 pm: Review of the Day

Location*: Potomac Salons D, E, and F.

Session Leaders:

- Jesse L. Berry, M.D. (see above for title).
- Helen Dimaras, Ph.D. (see above for title).

Wednesday, October 11, 2017

Potomac Rooms D, E and F (unless otherwise indicated)

7:30 – 9:00 am: Partner and Delegate Breakfast (invite only)

Location*: Chesapeake Salon B

8:00 – 9:05 am: Breakfast and Networking

9:10 – 9:20 am: Welcome Remarks and Introductions

Session Leaders:

- Jesse L. Berry, M.D., Scientific Program Chair, One Retinoblastoma World 2017; Associate Director of Ocular Oncology-Children's Hospital Los Angeles; Assistant Professor of Opthamology, USC Roski Eye Institute, Los Angeles, California.
- Marissa D. Gonzalez, President and Founding Board Member, World Eye Cancer Hope USA; Event Chair, One Retinoblastoma World 2017; Retinoblastoma Survivor.

9:20 – 10:15 am: Diagnosis and Staging

Session Leader:

- Ashwin Mallipatna, M.D., MBBS., Consultant Ophthalmologist, Adelaide Women's & Children's Hospital, Adelaide, Australia.

Session Participants:

- Helen Dimaras, Ph.D., Scientist, The Hospital for Sick Children (SickKids), Toronto, Canada; Assistant Professor, The University of Toronto, Canada.
- Brenda Gallie, M.D., Retinoblastoma Program Director, The Hospital for Sick Children (SickKids), Toronto, Canada; Professor, The University of Toronto, Canada; Co-founder, World Eye Cancer Hope.

Session Topics:

- What are the different staging and classification systems, and what do the different numbers/letters mean?
- What are the implications for treatment and survival?

10:15 – 10:30 am: Coffee Break

10:30 – 11:25 am: Treatment and Consent

Session Leader:

- Brenda Gallie, M.D. (see above for title).

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Session Participants:

- Brian Marr, M.D., Professor, Columbia University College of Physicians and Surgeons, New York; Director of Ophthalmic Oncology Service, New York-Presbyterian Hospital/Columbia University Medical Center, New York.
- Bhavana Chawla, M.D., Professor of Ophthalmology, Delhi University, New Delhi, India.

Session Topics:

- What are the different treatment options, when are they best used, and what are the benefits and risks of each?
- What can I do to make the best decisions for my child?

11:30 – 12:25 pm: Parent Advocate

Session Leader:

- Kaitlyn Hougham, MSc., Retinoblastoma Research Program Manager, The Hospital for Sick Children, Toronto, Canada.

Session Participants:

- Amanda Brody, M.S., CCLS, Certified Child Life Specialist, Solid Tumor Program, St. Jude Children's Research Hospital, Memphis, Tennessee.
- Sarah Green, MSN, CPNP-AC, Acute Care Certified Pediatric Nurse Practioner, Children's Hospital Los Angeles.
- Sarah Hancock, Mother of Damian, Naples, Florida.

Session Topics:

- How can I best prepare/support/advocate for my child during tests and treatment to protect their wellbeing?

REMINDER: Presentations and conference materials can be found in the DropBox Folder. (Link sent via email.)

12:30 – 1:45 pm: Lunch

Location*: Chesapeake Salons B and C

1:50 – 2:45 pm: Psychosocial Outcomes

Session Leader:

- Marissa D. Gonzalez (see above for title)

Session Participants:

- Len F. Burns, M.A., Licensed Marriage and Family Therapist, Santa Cruz, California; Retinoblastoma Survivor.
- Melissa Mills, MS, CGC, LGC, Genetic Counselor, Lucile Packard Children's Hospital Stanford, Palo Alto, California; Retinoblastoma Survivor.

Session Topics:

- A cancer diagnosis during childhood generates unique medical and psychosocial needs as developmental milestones throughout a person's lifetime are simultaneously impacted. What research is currently being done into psychosocial impacts and PTSD in diagnosed children, parents and adult survivors throughout their life, and how can we be involved to share our experience?

2:50 – 3:45 pm: Research

Session Leader:

- Jesse L. Berry, M.D. (see above for title).

Session Participants:

- Zelia Correa, M.D., Ph.D., Ophthalmologist, Cincinnati Children's Hospital, Cincinnati, Ohio; Associate Professor, University of Cincinnati, Ohio.
- Helen Dimaras, Ph.D. (see above for title).
- Mary Beth Aronow, M.D., Ophthalmologist, Johns Hopkins Hospital, Baltimore, Maryland.

Session Topics:

- How does clinical research work and what do I need to know about it in relation to my child's care?

For the following breakout sessions, delegates are invited to join one of five discussion groups. Refreshments provided.

3:45 – 4:15 pm: Breakout Sessions – Forward Planning

Location*: Chesapeake Salons B and C
Breakout Topics:

- Global Awareness Raising Efforts
- Developing Adult Survivor Life-Long Care
- Informed Consent & Evidence Based Medicine
- Engaging Families & Survivors in Research
- Developing Comprehensive Rb Programs & Integrated Family Support

4:15 – 4:45 pm: Group Discussion and Future Goals and Actions

Location: Potomac Rooms D, E and F
Session Leaders:

- Jesse L. Berry, M.D. (see above for title).
- Helen Dimaras, Ph.D. (see above for title).

4:45 – 5:00 pm: Review of the Day

Session Leaders:

- Jesse L. Berry, M.D. (see above for title).
- Helen Dimaras, Ph.D. (see above for title).
- Marissa D. Gonzalez (see above for title).

Delegates at the One Retinoblastoma World 2016 conference in Dublin, Ireland.

World Eye Cancer Hope
life and sight for every child

WE C Hope would like to thank everyone who donated their time and expertise to this year's One Retinoblastoma World Conference. To all of our sponsors, medical professionals, board members and volunteers, your help and guidance is very much appreciated. Thank you.

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