## Fourth Community Conference Agenda
### March 22 – 24, Boston, MA

**Friday, March 22, 2013 UNCOMMON STRENGTH**

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<tr>
<th>Time</th>
<th>Event</th>
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| 8:00am – 4:30pm | **Registration Open**  
*Location: 15th Floor Foyer* |                         |
| 10:00am – 12:00pm | **Peer Connect Support Meeting (By Invitation)**  
*Location: Beacon A* |                         |
| 12:15pm – 1:45pm | **Lunch Roundtables - Regional Peers:** Join us in the Chordoma Community Conference lounge to enjoy a casual lunch conversation designed to connect you to your peers from the same region.  
*Note:* Bring a lunch from one of the nearby restaurants. A list of suggestions is available at registration.  
*Location: Commonwealth A & B* |                         |
| 2:00pm - 3:00pm | **Alumni Reunion and Welcome to Conference:** Meet in CCC Lounge to settle in and get acquainted.  
*Location: Commonwealth A & B* |                         |
| 2:00pm – 3:00pm | **Chordoma 101 - Everything You Need to Know As You Start Your Journey:** An overview of the biology and treatment of chordoma and important concepts to consider for the new or recently diagnosed patient or caregiver.  
*Presenter: Chandranath Sen MD, Director, Benign Brain Tumor and Cranial Nerve Disorders Program, NYU*  
*Location: Beacon A* |                         |
| 3:15pm – 3:30pm | **Welcome and Kick-off Remarks**  
*Presenter: Heather Lee, Chordoma Foundation*  
*Location: Beacon A* |                         |
| 3:45pm – 5:00 pm | **Surviving and Thriving:** Hear from long-time chordoma survivors about what they’ve learned during their chordoma journey.  
*Location: Beacon A* |                         |
| 5:00pm – 6:00pm | **Fundraising Office Hours** – Have a question about your Champions page? Want help planning a great event? Interested in making a planned or estate gift? Deirdre will be available to answer questions, provide advice, and talk about different ways to help fund a cure!  
*Location: 15th Floor Foyer* |                         |
| 6:30pm – 9:30pm | **Dinner:**  
With Chordoma Physicians and Researchers  
Presentation of Awards to Researchers  
Live Entertainment  
*Location: Beacon Hill Ballroom* |                         |
| 9:30pm – 10:30pm | **Networking in the CCC Lounge**  
*Location: Commonwealth A & B* |                         |
### Saturday, March 23, 2013 UNCOMMON UNITY

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<th>Time</th>
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<tr>
<td>7:00am – 4:30pm</td>
<td>Registration Open</td>
<td>15th Floor Foyer</td>
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<tr>
<td>7:00am – 8:00am</td>
<td><strong>Breakfast Roundtables - Types of Chordoma:</strong> (Sacral/Spinal, Clival/Skull Base, Caregivers) Share a meal with those who may have similar diagnoses and challenges.</td>
<td><strong>Location:</strong> Beacon A &amp; B</td>
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<tr>
<td>8:00am – 8:15am</td>
<td><strong>Welcome and Highlights from the ICRW</strong></td>
<td>Beacon A &amp; B</td>
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| 8:15am – 9:45am | **Ask the Experts:** Your questions answered by expert physicians                         | **Presenters:**  
Gregory M. Cote, MD, PhD – Massachusetts General Hospital  
Paul Gardner, MD – University of Pittsburgh Medical Center  
Francis Hornicek, MD, PhD – Massachusetts General Hospital  
Norbert Liebsch, MD, PhD – Massachusetts General Hospital  
Robert Malyapa, MD, PhD – University of Florida Proton Therapy Institute  
**Location:** Beacon A & B |
| 10:00am – 11:15am | **Research Advances:** Learn about the latest discoveries and some of the most promising research that is advancing the understanding and treatment of chordoma. | **Presenters:**  
Adrienne Flanagan, MD, FRCPath, PhD – University College London  
Gary Gallia, MD, PhD – Johns Hopkins University  
Joseph H. Schwab, MD, MS – Massachusetts General Hospital  
**Location:** Beacon A & B |
| 11:25am – 11:55am | **Ask the Experts Panel:** Your questions answered by leading chordoma researchers        | **Presenters:**  
Adrienne Flanagan, MD, FRCPath, PhD  
Gary Gallia, MD, PhD  
Joseph H. Schwab, MD, MS  
**Location:** Beacon A & B |
| 11:55am – 12:15pm | **Chordoma Foundation Research Plan:** Learn what the Foundation is doing to accelerate the search for a cure, and about our plans to take advantage of unprecedented new research opportunities. | **Presenter:** Josh Sommer, Chordoma Foundation  
**Location:** Beacon A & B |
| 12:15pm – 1:30pm | **Lunch:** Presentation of Awards to Chordoma Champions                                       | **Location:** Capital A & B |
| 1:45pm – 5:30pm | **CCC Lounge Open:** Need a short break? Want to talk to a peer? Visit the Lounge and gather some information. | **Note:** If you have lost a loved one to chordoma, others who have faced a similar loss will be gathering in the lounge to support one another from 3:00pm to 5:30pm.  
**Location:** Commonwealth A & B |
| 1:45pm – 2:45pm | **A Call To Action! - You Can Make A Difference:** Members of the Chordoma Community often ask how they can help the Foundation work faster to find a cure. Join us for this “can do” session. | **Presenter:** Deirdre Callahan, Development Coordinator, Chordoma Foundation  
**Location:** Beacon A & B |
| 3:00pm – 4:00pm | **Concurrent Sessions**                                                                     | **Presenters:**  
Paula Rauch MD, child psychiatrist and director of the Marjorie E. Korff Parenting At a Challenging Time (PACT) Program will describe the ways parents can support their child's emotional health through the challenges of living and parenting with a chordoma.  
**Presenter:** Paula K. Rauch MD, Director, Marjorie E. Korff PACT Program  
**Location:** Capital A & B |
|               | **Navigating Clinical Trials – When is a Clinical Trial Right for You?** Learn about the different types of clinical trials, when it makes sense to participate in a clinical trial, and how to find and select the right trial, even those that don’t advertise for chordoma patients. | **Presenter:** Mrinal Gounder MD, Medical Oncologist, Memorial Sloan Kettering Cancer Center  
**Location:** Beacon A & B |
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| 4:00pm – 5:30pm | **Fundraising Office Hours** – Have a question about your Champions page? Want help planning a great event? Interested in making a planned or estate gift? Deirdre will be available to answer questions, provide advice, and talk about different ways to help fund a cure!  
*Location: 15th Floor Foyer* |            |
| 4:15pm – 5:30pm | **Concurrent Sessions**  
**Nutrition & Cancer - Living Healthy After Diagnosis**: This session will focus on educating, motivating, and empowering patients and their families to create a well-balanced diet geared towards well-being after diagnosis. We will touch on hot topics including sugar, organic versus conventional, and supplements as well as how to build an immune enhanced balanced diet. Nutrition management of treatment and cancer related side effects will be also be discussed to further demonstrate the power of food.  
*Presenter: Julia Hincman-Francavilla MS, RD, CSO, LDN, Clinical Nutrition Specialist, MGH Cancer Center*  
*Location: Beacon A & B*  
**Mindfulness - Meeting Stress with Awareness and Kindness**: Not only Eastern philosophers believe in a strong connection and symbiotic relationship between the mind and body; Western doctors and scientists have written extensively about how the mind body connection impacts one’s daily health. Learn simple activities to do at home to help strengthen your mind and body.  
*Presenter: Phyllis K. Hicks DMin, NCLPC, Senior Insight Dialogue Teacher, Metta  
Janet Surrey PhD, Insight Dialogue Teacher, Metta*  
*Location: Capital A & B* |            |
| 6:00pm – 6:30pm | **Group Photo**  
*Location: Beacon A & B* |            |
| 6:30pm – 8:30pm | **Dinner**  
*Celebration of Life*  
**Keynote: Doug Smith - “The Skill of Happiness”**  
Doug Smith is a retired business executive devoted to helping people live and lead more abundantly. He is deeply intrigued by what enables certain people to live with incredible joy and exuberance no matter what fate hands them and how certain leaders enable their organizations to achieve superior results no matter what the business environment. During the past 15 years he has served as CEO of Kraft General Foods Canada, Chairman/CEO of Borden Foods Corporation and most recently Chairman/CEO of Best Brands Corporation. Today he speaks on happiness and on leadership at numerous venues throughout the country, he also teaches at DePauw University and at Canyon Ranch. He devotes 100% of the compensation he receives to cancer research. Doug has a BA and an Honorary Doctorate from DePauw University and an MBA from the Tuck School of Business at Dartmouth.  
*Location: Capital A & B* |            |
| 8:30pm -10:00pm | **Networking in the CCC Lounge**  
*Location: Commonwealth A & B* |            |
### Sunday, March 24, 2013 UNCOMMON PERSEVERANCE

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<td>7:30am – 11:30am</td>
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<td>7:30am – 8:30am</td>
<td>Breakfast Roundtables – Years since diagnosis: (0-5 years, 5-10 years, 10+) We experience different challenges at different stages on our path with chordoma. Come and gather hope and inspiration from others.&lt;br&gt;&lt;br&gt;&lt;strong&gt;Location:&lt;/strong&gt; Beacon A &amp; B</td>
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<td>8:45am – 9:45am</td>
<td><strong>Concurrent Sessions</strong>&lt;br&gt;&lt;br&gt;<strong>Mindfulness - Meeting Stress with Awareness and Kindness:</strong> Not only Eastern philosophers believe in a strong connection and symbiotic relationship between the mind and body; Western doctors and scientists have written extensively about how the mind body connection impacts one’s daily health. Learn simple activities to do at home to help strengthen your mind and body.&lt;br&gt;&lt;br&gt;&lt;strong&gt;Presenter:** Phyllis K. Hicks DMin, NCLPC, Senior Insight Dialogue Teacher, Metta&lt;br&gt;Janet Surrey PhD, Insight Dialogue Teacher, Metta&lt;br&gt;&lt;br&gt;&lt;strong&gt;Location:** Capital A</td>
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<td><strong>Palliative Care - It's Not What You Think:</strong> The World Health Organization writes, “Palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life and includes those investigations needed to better understand and manage distressing clinical complications.” This workshop will address misconceptions about palliative care and how we might make use of it at any stage of our journey with chordoma.&lt;br&gt;&lt;br&gt;&lt;strong&gt;Presenter:** Anthony Galanos MA, MD, Associate Professor of Medicine, Duke University Medical Center&lt;br&gt;&lt;br&gt;&lt;strong&gt;Location:** Beacon A &amp; B</td>
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<td>10:00am – 11:00am</td>
<td><strong>Concurrent Sessions</strong>&lt;br&gt;&lt;br&gt;<strong>You're in The Driver's Seat - Patient Navigation:</strong> Navigating the American medical system can be enormously challenging, whether you are newly diagnosed, have had a recurrence or are currently living disease free. In this session, learn steps for effective self-advocacy and partnership with your health care team, how best to coordinate care among different hospitals, how to deal with insurance denials, and more.&lt;br&gt;&lt;br&gt;&lt;strong&gt;Presenter:** Al Ferrera RN, Massachusetts General Hospital, Harris Center for Chordoma Care&lt;br&gt;&lt;br&gt;&lt;strong&gt;Location:** Beacon A &amp; B</td>
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<td>10:45am – 11:45am</td>
<td><strong>Scanxiety - How To Cope:</strong> Whether you are 6 months out from treatment, or 10 years, you might still feel “scanxiety”. This is a common anxiety people experience while waiting for test results. Learn how to manage your anxiety and take away new strategies to use when preparing for your scan, while you are in the midst of the procedure, and while you wait for the results.&lt;br&gt;&lt;br&gt;&lt;strong&gt;Presenter:** Kelly M. Trevino PhD, Clinical Psychologist and Research Fellow, Dana-Farber Cancer Institute&lt;br&gt;&lt;br&gt;&lt;strong&gt;Location:** Capital A</td>
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<td>11:15am – 11:45am</td>
<td><strong>Conference Wrap-up &amp; Next Steps</strong>&lt;br&gt;&lt;br&gt;&lt;strong&gt;Location:** Beacon A &amp; B</td>
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<td>1:00pm</td>
<td><strong>Optional Outings</strong>&lt;br&gt;&lt;br&gt;Visit the Proton Beam Center at Massachusetts General Hospital</td>
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