

Winter 2014



Melorheostosis
ASSOCIATION

"The greatest degree of inner tranquility comes from the development of love and compassion. The more we care for the happiness of others, the greater is our own sense of well-being."

*Tenzin Gyatso,
the 14th
Dalai Lama*

The President's Corner

Hello Melo Community!

Time for another Melorheostosis newsletter. Read on to learn more about a Melo patient's firsthand experience with Melo research, hear details about our upcoming 2014 conference, and to get to know more of our Melo community. Don't forget about our next Melo Conference this coming October 23-25, 2014, at the Doubletree Rochester near the Mayo Clinic in Rochester, Minnesota.

Read on to learn more and stay tuned for registration information on this conference. We hope to see you there!

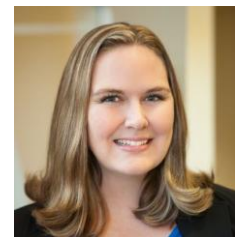
Also, if you haven't joined our Facebook Group "Melorheostosis Patients and Friends" – come join the conversation. Here you can share about yourself or read about others – email Amanda if you would like to join this group. We are all here to support each other and help you to know you are not alone!!

Thank you so much Katrina Wells for setting it up!

Let us know if you would like us to focus on anything special in the next issue or if you would like to participate in the "Getting to Know You" section of the next newsletter.

ONWARD!!

Jen



Save the Date and Sign Up NOW!

2014 Melorheostosis Conference
October 23-25, 2014
Mayo Clinic, Rochester, MN

Save the date for our next Melorheostosis Conference! If you have ever considered coming to a conference, THIS IS THE ONE! We are welcoming new patients, as well as returning patients who have attended in the past years. The lodging will be at the Doubletree by Hilton in Rochester. Scholarships for airfare will be available upon request and hotel rooms will be covered by the Association thanks to the generous work of Stephanie Papke and the MeloFund! A HUGE thanks to them and the work they do.

All you need to do to sign up is fill out and send in the registration form in the email with this newsletter along with a deposit check which will be returned to you once you check in at the conference.

Please don't miss this incredible opportunity to learn more about the disease as well as meet esteemed members of our Medical panel, Mayo Clinic doctors and others who have Melorheostosis! If you have questions about the conference contact Jen at gordjym@yahoo.com



Sajjad Hossain Tuhin

The only known melorheostosis patient in Bangladesh shares his story

"What you thought before has led to every choice you have made, and this adds up to you at this moment. If you want to change who you are physically, mentally, and spiritually, you will have to change what you think."

Dr. Patrick Gentempo



I was a little restless and sporty from my childhood. My eldest brother put me into Judo lessons when I was only 6 and I used to come back home with pain in my right foot and leg from my judo classes. Everybody thought it might be from the Judo lesson or motion or growing pain. But finally when I went to the doctors, the x-ray reports seemed very strange to them. My eldest brother had taken me to a couple of doctors but to no avail. When I turned 13 or 14, an orthopedic surgeon named Dr. Salek Talukder, diagnosed the disease as melorheostosis. He advised me to avoid all kinds of sports which could affect or injure my foot or leg.

I was fine and I had pain (which sometimes became horrible) on my right foot and normally it never stayed more than 6/7 days. But in the last few years I found that the duration of the pain is increasing and almost all the time I have pain on my right foot - mainly it becomes worse after sitting for several times or getting up from bed in the morning and if I stand for a long time, also in cold weather. Apart from that, I have mild numbness in my right leg and hip. I went to different doctors in Bangladesh, Thailand and India, just to get an answer - What is next? How long I will suffer like this? Will this pain increase with the passage of time? Will it spread to other parts of my body? No Answer. Nobody could advise me.

I was feeling helpless as nobody had any idea about it. And it became really difficult for me to share it with anybody - and I tried not to discuss it. I even stopped doing x-rays and talking with doctors here as they started asking too many questions because they don't have any idea about this case. And going abroad for treatment is too expensive.

Finally, my wife helped me out finding the melorheostosis website for me.... It is really helpful and I am feeling really strong that now we are a team and we could do something. And on top of this there are lots of specialists who are doing research and working on this. I was in touch with Ms. Kathleen and Ms. Jen of our Association; and in 2009 I had the opportunity to attend the Melorheostosis Conference in Washington DC where I met with other Melo patients like me and doctors who are working for us. It was a wonderful experience of attending the conference and meeting the nice people of our association.

By that time, I have had almost all types of pain killers. BUT now I am trying to reduce taking the medicine (pain killers). I learned how to live with pain and how to manage it. It's true that I have unbearable pain which occurs not more than once or at best twice in a month and which never stays more than 6/7 days. I took it as a part of my life and convinced myself that I have to live with this disease and the pain. Swimming helps me a lot.

Love and best wishes to all out there who are in the same problem with this rare disease. I wish someone will come up very shortly with some advice - what to do and how to live with it.



Tissue Donation

By Joanne Chapman



Hi All, My name is Joanne and I have Melorheostosis in my right leg, from my big toe to the groin. I noticed it when I was approximately 8 years old.

I am so grateful that I found the Melorheostosis website in 2010 and attended my first conference in 2011. During my second conference in 2012 I was overwhelmed by the care, concern and effort that Dr. Mortier (from Belgium) had for our association and the Melorheostosis disease. It was evident to me that the limited number of human tissue samples and the preservation of tissue donation was/is quite a problem.

Therefore, without hesitation, I volunteered to travel to Belgium, at my own expense and have surgery on both legs. Dr. Mortier and his team decided to chisel bone from my right tibia and take a biopsy from my left upper/inner thigh. March 2013 I flew to Belgium where Dr. Mortier and his team welcomed me with open arms! They took the very best care of me and three short days later I walked out of the Belgium hospital (UZA) on my own!

The healing and recovery process went better and faster than I had expected. Dr. Mortier was hopeful that my tissue donation and his research would uncover an answer to a slow, stop or a cure for this rare and painful disease. My tissue

donation, especially since it did not have to be preserved was very helpful for Dr. Mortier and his team. There were no conclusive results from “my” sample, but we are on the right track.....I absolutely believe in Dr. Mortier, his team, and the extensive research he has done. I urge you to consider Melorheostosis tissue donation whether it be preserved by the Mayo Clinic or you choose to travel to Belgium.

I am passionate that we can, and will, find a slow, stop, or a cure to this 1 in a Million—painful and debilitating disease. I have attached the letter I wrote after surgery in my Belgium hotel room.

Love & Peace Joanne Chapman

A Letter

By Joanne Chapman

As I write the date, I can hardly believe it myself. Just four short months ago, I knew the journey I wished to conquer— having no idea what it would take to complete. It came together like the clouds of a rain storm and in the end a rainbow appeared. I did it without hesitation or reservation. The strength was deep within and was honestly effortless.

I reflect back in amazement to a journey that I would take alone through four countries, airports, hotels, and a hospital in a foreign land. Of course, thanks partly to technology, I

traveled alone, rented a car, drove over 180 kilometers, and voluntarily had surgery on both legs.

Already knowing the outcome could only be positive. Whether the conclusion arises from this effort or not, the path has already been paved. The original plan was to have bone samples taken from each leg.

After pre-op, the decision was to chisel pieces of the “concrete-like” bone from the right tibia and take only a biopsy from the upper left thigh. Ironically, the operating room at the UZA in Belgium is called the Operation Theater and is referred to as the OK, opposed to the OR. (Ironic)

A release of emotion came in the form of tears prior to the anesthesia. Oddly enough, I came out of the anesthesia crying as well. For two days I shared a hospital room with Monique. Monique, 10 years my elder, rides her bicycle to work (at the Coca-Cola plant) every day-64 kilometers!

Continued on next page



A Letter (continued)

"The gem cannot be polished without friction, nor man perfected without trials."

Chinese proverb

Two weeks ago, on her way to work, she was hit by a truck. The driver of which never saw her and never hit his breaks! Both legs were severed! She explains to me that she was conscious immediately following the accident and that she felt NO PAIN! The reattachment of both legs was successful at first. Days later, complications with the left leg, led to it being removed at the knee.

I was awestruck by her faith and determination as she tells me-She Will Ride Again! Monique and I do not speak the same language, we do not live in the same country-- but, we were connected and understood each other. Sitting in the chair between our beds on day two of my stay, I knew she was describing the accident to a friend by phone. (In spite of our language barrier) I reached over and held her hand for the duration of the call.

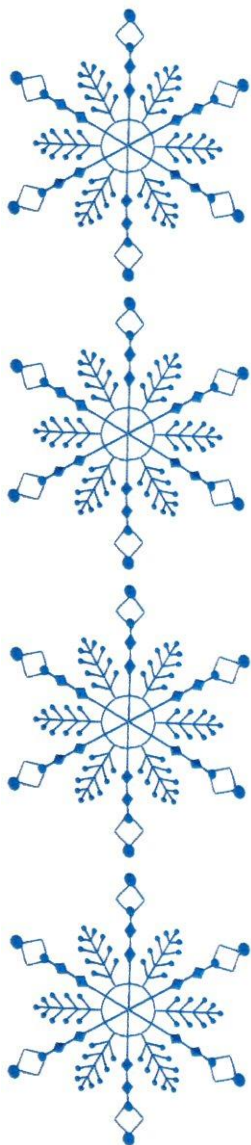
After breakfast that morning, the doctor indicated that I would be discharged that afternoon. With broken English, Monique shares "I don't like this- I don't like this!" "I will never see you again!" She proceeds to tell me how courageous and strong I am to come to Belgium for my surgery. I, of course, see that and more in her! I explain to her that she was MY blessing and I know full heartedly, she will find hers. That afternoon, I leave the hospital upright and walking on my own. As I leave the hospital in search of a taxi, I am surrounded by a 1/2 dozen roosters on the pathway.

The next day after being released from the hospital, I set out to downtown Antwerp to find my friend Monique a gift. In the front window of the first store I walked to, I find a set of Angel Wing necklaces. The sales clerk puts one necklace on me and wraps the other for Monique. The most profound part, is that the clerk put the Right side of the angel wing on me (hence the Melorheostosis in my right leg) and that meant the left side was for Monique. (Hence her left leg being amputated at the knee) The very next store had a costume jewelry necklace with a bicycle. The pedals were movable, symbolizing to me that her pedals will move again! Returning to the hospital to give Monique my gift of love; I find her sleeping, as she has just come from the OK. They amputated another half of her left leg! As she awakens with a smile, we cry-we hug! She says to me once more, "I must RIDE again! "I KNOW SHE WILL! We are so blessed, regardless of the time, space or appearance.

I couldn't feel more grateful and fulfilled with my trip of solitude, reflection, and enlightenment. If only my words no matter what language, could express all my eyes, heart and mind took in. As I listened to The Voice Within, written by Glen Ballard and sung by Christina Aguilera, I think: They call it Chronic Pain, Chronic Disease. ***I hear, but choose not to listen. *** (looking at the written word (chronic) I notice the latter part is...on--I--see) my choices are hardly try or try harder. I have heard in yoga that pain is weakness leaving the body.

THEREFORE, I AM STRONG!

By Joanne Chapman



Contact Information

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To contact Melorheostosis Association via email, contact Jennifer Gordy, President gordyjm@yahoo.com

We're on the Web!

See us at:

www.melorheostosis.org



The Melorheostosis Association is a 501(c)(3) not-for-profit organization dedicated to finding the cause, treatments and cure for melorheostosis. Our focus is on promoting greater awareness and understanding of this progressive disease and its manifestations through education, research, communication, and advocacy efforts on behalf of those affected by it as well as those dedicated to

alleviating it. For a full list of our Board of Directors, go to our web site. [www.melorheostosis.org]. Our world renowned Scientific and Medical Advisory Panel is led by Dr. Geert Mortier, Director, Department of Medical Genetics Antwerp University Hospital, Belgium.

Melorheostosis.org is:

- the largest database of melorheostosis patients in the world
- a community of melorheostosis patients and their families joined to share information, offer support, and seek answers together
- a source of information for treating physicians, researchers and other professionals

Melorheostosis in the News

Wouldn't it be great if we can keep this unusual and rare disease in the news?

What is Melorheostosis?

Melorheostosis is a rare and progressive disorder characterized by hyperostosis (thickening) of the cortical bone. Melorheostosis affects both bone and soft tissue growth and development. Melorheostosis can result in severe functional

limitation, extensive pain, soft tissue contractures, and limb, hand and/or foot deformity. The age of diagnosis is typically based on the severity of onset and symptoms. On x-rays, the appearance of melorheostosis has been likened to flowing, melted

candle wax.

Note: Diseases associated with melorheostosis include, osteopoikilosis, osteopathia striata, scleroderma and Buschke-Ollendorff syndrome.

Please Consider a Donation

The Melorheostosis Association is an all-volunteer charitable organization of patients and parents of patients. Every dollar you donate goes directly to our mission to find the cause, treatments and a cure and is tax deductible.

Please donate on the website, www.melorheostosis.org or send a check to:

Melorheostosis Association
410 East 50th Street
New York, NY 10022

Donations of any size are very welcome and greatly appreciated.

Willing to help?

Please contact us if you are interested in helping or being a part of our board of directors. Since we are an all volunteer organization, we always appreciate help with planning conferences, fundraising, putting together newsletters, etc. We welcome anyone willing and able to serve in this manner!

Tell us what you think!

We always welcome your feedback. Please let us know if you would like to hear about a specific topic in the next issue or if you would like to participate in the "Getting to Know You" section of the next newsletter.

Association Mission.....

The Melorheostosis Association is a 501 (c) (3) not-for-profit organization dedicated to finding the cause, treatments, and cure of Melorheostosis. Our focus will be on promoting greater awareness and understanding of this progressive disease and its manifestations through education, research, communication, and advocacy efforts on behalf of those affected by it as well as those dedicated to alleviating it.

2014 Melorheostosis Association Officer and Directors

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Joanne Chapman	Treasurer	Dallas, TX	joanne@chapmanrealty.com



“Nature is nowhere accustomed more openly to display her secret mysteries than in cases where she shows traces of her workings apart from the beaten path; nor is there any better way to advance the proper practice of medicine than to give our minds to the discovery of the unusual law of nature, by the careful investigation of cases or rarer forms of disease.”

William Harvey, 1657

Susan Dunaway – Melo Newsletter Editor