LFSA

YOUTH NEWSLETTER

FALL 2020

Meet Dr. Mary-Louise Greer!

Dr. Greer has been on staff as a pediatric radiologist in the general division at the Hospital for Sick Children in Toronto, Canada since June 2011. Mary-Louise undertook her medical and radiology training in Brisbane, Australia, becoming a Fellow of the Royal Australian and New Zealand College of Radiologists in 2000; completing Fellowships in pediatric body imaging and body intervention in 1999/2000 and cardiac MRI in 2009/10 at SickKids. When Director of Radiology at the Royal Children's Hospital in Brisbane between 2003 and 2006 she helped establish the Queensland Pediatric MRI service, serving as President of the Australian and New Zealand Society for Pediatric Radiology in 2008/09. In 2014 Dr. Greer was appointed Co-Head of Body MRI at SickKids. Mary-Louise's clinical, teaching, and research interests focus on advanced MRI applications in pediatrics, including whole body and diffusion weighted imaging in oncology, inflammatory bowel disease, and general anesthesia alternatives in MRI. She is investigating clinical applications of contrast enhanced ultrasound.

Why did you choose the field of radiology as your profession?

I've always wanted to work with children. I went to medical school hoping to become a pediatrician, always remembering the wonderful pediatrician who'd looked after me as a child, Dr. Ron O'Reilly (and his jellybean jar!).

When I was a junior doctor, I started training in pediatrics. To my surprise I found I really liked the more technical part of medicine, Pediatric Radiology, working with all sorts of imaging equipment and doing procedures to help problem solve, but still working with children and their families. I needed to study more anatomy and physics to do this and luckily, I like both.

I should mention my father was a radiologist. As I'd wanted to do my own thing, I hadn't properly considered it early on. When I told him that I wanted to change track and do Radiology he was very cute, worried he might have talked me into it! He hadn't. Becoming a specialist is a long road, you have to want to do it yourself. However, my dad was a huge help when I was training, reading the MRI physics book out of interest even though he'd already retired and discussing it with me, no doubt where my passion for MRI began!

What is your favorite part about your job?

Interacting with my patients and their families, especially when I get a wave or smile from a young patient after a scan or procedure is over. Being part of a team working with my technologists and clinical colleagues managing our patients' medical problems, hopefully helping them find some answers - it's like being a detective.

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Dr. Greer Continued

Are there any misconceptions that you've noticed people can have about radiologists or radiology in general?
I think a couple of misconceptions are that radiologists spend all their time sitting alone in a dark room, and that we don't like to talk to people.

While I do spend some time "sitting alone in a dark room" reporting (it helps us see the images better), it's only part of my day. It also involves planning and checking scans with the technologists, doing scans and procedures engaging with my patients and their families, reviewing imaging studies with radiology trainees and the clinical teams, and teaching. Radiology really is a team sport! This year more interactions are virtual instead of face-to-face due to COVID-19. So radiologists, in particular pediatric ones, LOVE talking to people.

In your opinion, why is the whole body MRI the best option for surveillance screening for patients with Li-Fraumeni Syndrome (as opposed to other imaging methods such as CT, PET, X-ray)?
This is a good but tricky question to answer.

Whole body MRI (WBMRI) by definition is able to assess large areas - head to toe, showing the solid organs, bones and soft tissues well without needing ionizing radiation used by the other techniques you mention. Ionizing radiation confers a small potential risk of cancer, exact risk under debate, but the risk is considered a little higher if you have LFS.

WBMRI helps us detect a range of different tumors early on, especially ones like osteosarcoma and soft tissue sarcoma, ideally when small and before they are symptomatic. The reason we try and detect them at this stage is based on the principal that most tumors are easier to treat with better outcomes when detected early.

No single test is perfect which is why in LFS and other cancer predisposition syndromes WBMRI performs best when correlated with the rest of the surveillance protocol. In the LFS protocol, this includes other imaging - brain MRI and abdominal ultrasound, lab tests and clinical assessments. Used together, it helps us improve detection of tumors and manage "false positives", things that might show up on WBMRI because it is so sensitive but that we don't want to overcall as a tumor. This is a common challenge with any surveillance test.

What role does contrast play in MRIs?
In MRI, we use gadolinium-based contrast agents. We don't use contrast routinely for surveillance WBMRI or after the first baseline brain MRI. This is because we don't think it adds enough extra information to justify giving it every time. Plus it means getting an IV. However, if we see a lesion on WBMRI or brain MRI then we might give it if we think it can help characterize it better, helping us work out our level of concern. Contrast might be given at the time of the WBMRI or brain scan, or at a different time if we need a separate, more detailed MRI scan of an area.

What is the most interesting thing you've seen on a patient's imaging?
I once had to do whole body MRI scans on two babies at the same time - conjoined twins. Their imaging showed where and how they were connected. The parents had permitted "60 Minutes" in Australia to tell their babies' story, so supervising this MRI with my colleague Steve was even more interesting than usual as we were also being filmed.

What do you like to do on your days off/for fun?
I love cooking, reading and going for walks with my chocolate Labrador Ned. We recently went camping up around Lake Superior which was great fun, so beautiful.

If you could travel anywhere in the world, where would you go and what would you eat first?
Top of my list at the moment is Australia to see my family and friends. I'd have dinner with them at my favorite restaurant at Main Beach on the Gold Coast where you can sit on a deck overlooking the water and eat chilli plum bugs (Moreton Bay bugs are like little lobsters).

2020 Youth Workshop – A Virtual Success!

Wow! The 2020 Virtual Youth Workshop was a wonderful success, and while different than in years past, this year's Workshop gave our 40+ participants a wonderful opportunity to hear the latest in LFS research, speak to leading doctors in the field about difficult choices in their healthcare, and receive encouragement while being connected to a supportive community, all from the comfort of their own homes.

The first half of the day was for our participants aged 13-17, and included conversations with Dr. Josh Schiffman and Dr. Maria Isabel Achatz about their research and helpful tips on nutrition and lifestyle habits for cancer prevention, including how to stay watchful for any changes in their bodies. We learned more about Dr. Josh's favorite gene - TP53, the different nuances to what it actually means to have Li-Fraumeni Syndrome, and even completed an interactive pop quiz competition with the doctors after the sessions were over!

The second half of the day was devoted to 24 participants aged 18-25. Dr. Kara Maxwell and Jaquelyn Powers, MS, LCGC discussed the realities, difficulties, and anticipation of transitioning to adult healthcare. Participants were able to ask Dr. Maxwell and Jaquelyn their questions regarding prophylactic procedures, imaging, and family planning - all topics that our youth participants have inquired about in previous years. We were thrilled to finally be able provide our participants with the unique opportunity to speak to the leading experts on these subjects, without any geographical or financial hurdles in the way!

The day ended with more conversations with Dr. Schiffman and Dr. Achatz, from reproductive studies to demystifying key terminology used in genetics regarding LFS. Fun fact: did you know that, according to Dr. Achatz's research, there are as many as 1 in 500 people in the world living with LFS? This is quite a difference from the previously estimated amount: 1 in 10,000!

Thank you to everyone who worked so hard to make this Workshop a wonderful success, including Meghan O'Keefe, Anna Joy Ryan, Olivia Naves, and Isabel Costa, and a very special thanks to all of our youth participants! You all helped to prove that, no matter the limitations in place because of the circumstances in the world around us, it is still more than possible to come together to learn, connect, and grow in confidence and understanding as we strive to live boldly in the world with LFS.

Cameron Block
USA Youth Chair, LFSA

Meet Caley Kling!

Where do you live?
I live in Littleton, Colorado (a town near the foothills of the Rocky Mountains).

Tell us about your family!
I have three younger siblings-two brothers-David (14), who loves sports, and William (6), who loves playing, and a younger sister named Adelyn (4), who loves to dance. Adelyn is the only other sibling with LFS. My parents are Dave and Lynsey Kling. My dad is the only parent with LFS.

What are your favorite hobbies or activities?
I like to Wrestle and Bake when I have free time. I wrestle for my high school, and have placed at/gone to a few national tournaments. I was a state qualifier this year as well.

What would you like to do or study in the future?
I would like to become a genetic counselor or nurse in the future, so that I can help people with situations like LFS.

What is one way that your LFS diagnosis has impacted you for the better?
Having the diagnosis has given me the opportunity to get screened for cancer often, which is something a person without LFS wouldn't be able to do. I am glad that if I do get cancer, it has a better chance of getting caught early because of the screening.

What is one good thing you have enjoyed or experienced in 2020 so far, despite the difficult circumstances?
I have enjoyed spending time with friends, even at a distance, and eventually being able to wrestle.

If you could travel anywhere in the world, where would you go and what would you eat first?
If I could travel anywhere in the world, I would go to France and try fresh baked goods from a French bakery.

What is one piece of advice you would give to another teen who has LFS?
If I could give any advice, it would be to stay positive, and look for the good in every situation.

UPCOMING EVENTS