

AHEAD OF THE CURVE

The Official Newsletter of The Setting Scoliosis Straight Foundation

YOUR VOICE IN ACTION: OUR PATIENTS SPEAK!

VOLUME 7, ISSUE 1



THE BRIDGE YOU BUILT

“Just because it’s pink, doesn’t mean it’s cute,” **Eve Moll** told a laughing audience. She was talking about the brace she’d worn for a year and a half. The brace that was supposed to stop her curves from progressing. The brace that didn’t work. Eve Moll was having surgery. But she was an athlete! Her health had been perfect her entire life! Why was this happening?

Eve is a survivor, and so, she survived. Eve is an artist. After her surgery, she processed her experience by drawing it, and she donated a giclee of her drawing “On My Way” to SSS to be auctioned at the gala. During her speech, Eve explained the meaning behind her painting, which shows a girl standing alone on a bridge. The bridge, Eve shared, is what allows the girl to make it past danger and continue with her life’s journey. The bridge represents the rods and screws in Eve’s back. As members of the audience dabbed tears from their eyes, Eve said, “Thank you for your countless hours of effort and research, for your immeasurable dedication to patients like me, and for your heroic efforts of developing and improving scoliosis treatment. Thank you for building my bridge.” She was thanking YOU for your support.



AN ALPINE SPINE MADE OF MEDALS

When **Katie Lyons** was diagnosed with scoliosis at age fifteen, Web MD didn’t exist. Online scoliosis support groups weren’t a thing. Books she read about spine surgery were full of doom, and they promised a life of limitations. Don’t and can’t seemed to be the words she heard the most, and Katie was horrified. After all, can you imagine how crushing the thought of permanent limitations would be to a world-class, competitive alpine skier at age fifteen? But can you also imagine how great it would feel to meet a surgeon who confidently said, “I can get you back to skiing?” Hope is such a wonderful thing.

Yes. You helped Katie get back to skiing after her surgery. And if you’d like to know how well she did, even with all of the rods and screws in her back, her surgeon’s office in San Diego holds a clue. One of Katie’s medals lives there, proudly on display.



2015
Marks Our
20th
Anniversary

Visit our website for more details.

www.settingscoliosisstraight.org

Follow Us



RESEARCH SITES

BC Children's Hospital, VAN
Sameer Desai -
Sameer.Desai@cw.bc.ca

Children's Hospital of PA
Michelle Ho -
mho@email.chop.edu

CHU St. Justine of Montreal
Marjolaine Roy Beaudry -
Marjolaine.beaudry@recherche-ste-justine.qc.ca

Washington University, STL
Kathy Blanke -
blankek@wudosis.wustl.edu

Johns Hopkins Hospital, MD
Craig Remenapp -
cremena1@jhmi.edu

Miami Children's Hospital, FL
Rafaela Solano -
Rafaela.Solano@mch.com

Nemours Children's Clinic, DE
Geraldine Neiss -
geraldine.neiss@nemours.org
Petya Yorgova -
petya.yorgova@nemours.org

Philadelphia Shriner's, PA
Kim Hayes -
khayes@shrinenet.org

Rady Children's Hospital, CA
Carrie Bartley -
cbartley@rchsd.org

Scoliosis & Spine Associates, NY
Yuan Ren -
blonner.spineresearch@gmail.com

University of Virginia, VA
Mark Feger -
MF3DE@hscmail.mcc.virginia.edu

Executive/Research Director
Michelle Marks -
mmarks@ssshsg.org

THE FUTURE OF AIS

Is Tethered to You

Can you imagine standing alone, under a spotlight, on a stage in a room filled with three-hundred people? Almost all of them are strangers, and they all have their eyes on you. There is a microphone in front of you that your dad just used to introduce you. You're holding a page that tells your scoliosis story, and you are sharing a very personal part of your life with the entire room. You're explaining to the room that your back has a secret. It isn't full of rods and screws. It's tethered, and the future of AIS is tethered to you. Now, if you can imagine that, imagine this: your name is **Emma Sayar**, you're twelve years old, and you are one of the bravest girls in the world!



BENT NOT BROKEN

Brace after brace after brace didn't stop **Natalie Yerushalmi-Lewis'** scoliosis from progressing so rapidly that she ran the risk of having her organs collapse. Surgery was inevitable, and when that day came, Natalie arrived at the hospital equipped with Build-a-Bears from each of her family members. "Mommy, remember that no matter what happens, it's not your fault" and "I love you" were the words she said as she walked away from her family toward the operating room. Today, Natalie is getting ready to start her own family, and fourteen years after her surgery, she still has questions.

Does having spinal surgery affect pregnancies and make them harder? Will her children have AIS?

As Natalie told her story, it became crystal clear that what matters most to her is family. She asked each of you to remember that the work you do could never be reduced to just medical procedures, studies, or research. The work you do changes real lives, or as Natalie says, you help fix "real people who are bent but not broken."



Spine bracelet designed and donated by Natalie Yerushalmi-Lewis

DON'T FORGET! As a patient volunteer for the **Harms Study Group**, your continued help is essential. Please remember to make all of your scheduled follow-up appointments with your spine surgeon.

www.settingscoliosisstraight.org