

## Remembering Gemma Geisman

*It is with great sadness that the OI Foundation's Board of Directors and Staff report that Gemma Geisman, founder of the OI Foundation, has passed away.*

*More than fifty years ago, Redbook magazine published an article written by Gemma Geisman about her 11-year-old son, Mike, who was living with osteogenesis imperfecta. Gemma wrote about the challenges they faced as a family, including the isolation and the frightening lack of information or support for caring for a child with a rare fragile bone condition. Gemma's words reached families with OI across the nation. Letters started flooding her mailbox and within months, a committed group of parents came together to support each other. In 1970, the OI Foundation was formed.*

*Gemma, with the help of a small group of parents, made it her mission to bring information and support to families with OI. Gemma was involved in publishing the first issue of the OIF Breakthrough Newsletter, creating the first brochure about OI, establishing the OI support group network, organizing the first OIF National and Regional Conferences, and so much more.*

*This year is the OI Foundation's 50th anniversary year. The OI Foundation would not be here today without Gemma's dream to bring information and support to families with OI.*

*We owe a very special thank you to Gemma for her dedication to the OI community for more than fifty years. She will be greatly missed.*

### **Gemma Marquis Geisman 85**

peacefully passed away on Thursday, April 23, 2020. She was born in Van Buren, Maine, on December 7, 1934, and was proud to be number 12 of 13 children born to William and Adele (Castonguay) Marquis.

Gemma married the love of her life Richard "Dick" Geisman on June 27, 1953 at St. Anne's Catholic Church in Hartford, CT,

and they shared 54 wonderful years together before his passing on September 30, 2008. Gemma had plans to be a nun after graduation until Dick, a navy sailor, "crashed" a wedding she was attending. It must have been divine intervention as they were truly meant for each other.

Gemma was a loving mother to her four children and in spite of the fact that her second child, Mike, was born with a rare genetic brittle bone disease called Osteogenesis Imperfecta, she and Dick did everything they could to create a normal family life for all. Their home became the hub of the neighborhood, with wiffle



(continued on page 2)

## OIF National Conference Update

After careful consideration, the OIF's Board of Directors and OIF Staff have postponed this summer's OIF National Conference. Although we are disappointed that we will not be able to come together this summer, the health and safety of the OI community comes first.

### **Please note the new OIF Conference schedule:**

July 10-12, 2020 – Virtual OIF Conference

July 8-11, 2021 – OIF National Conference; Omaha, Nebraska

July 7-10, 2022 – OIF National Conference; Orlando, Florida

Conference Postponement Considerations

1. *Conference Registration* – All registrations for the Omaha 2020 National Conference have been automatically transferred to the 2021 OIF National Conference. If you are unable to attend the

rescheduled Conference on July 8-11, 2021, please contact the OI Foundation or cancel your registration directly through your registration confirmation page.

2. *Hotel Reservations* – Please contact the Hilton Omaha Hotel at (402) 998-3400 to cancel your hotel reservation.

A graphic with a dark blue background. At the top left is a laptop icon with a green 'CELEBRATE' banner. To its right, the text 'VIRTUAL OIF CONFERENCE' is written in white, with 'JULY 10-12, 2020' in yellow below it. Below this, 'OIF NATIONAL CONFERENCE 2021' is written in white, with 'OMAHA, NEBRASKA // JULY 8-11, 2021' in yellow below it. At the bottom, 'OIF NATIONAL CONFERENCE 2022' is written in white, with 'ORLANDO, FLORIDA // JULY 7-10, 2022' in yellow below it.

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## Remembering Gemma Geisman (continued from page 1)

ball games causing a permanent infield in the grass, homemade ice cream being cranked and shared with all, Christmas trees bigger than life, pulling taffy, making fudge, camping and many more activities that have become family traditions. Her children could always count on her to sweep away the boredom of a lazy summer day by writing a script for a summer play with them as the main characters and the neighborhood children as the audience. Gemma was the producer, director, set designer, costume designer, acting coach and marketing genius. Because of her love of reading there were many trips to the local library and piles of books coming home for the children to read.

Gemma was very creative and had a passion, not only for reading, but for writing stories. She is the published author of over 60 articles that have appeared in various magazines such as *Redbook*, *Good Housekeeping*, *Lady's Circle*, *Exceptional Parent*, *American Legion Magazine*, *Catholic Digest* and many others. Her favorite topic was sharing the joys of growing up in a small town in Northern Maine in a large French-Canadian family in the "House on the Hill".

Gemma's writing led her to submit a Young Mother's Story to *Redbook Magazine* in 1967 called "My Prison of Dreams" which was the story of how it felt to care for a breakable baby with Osteogenesis Imperfecta. The publication of this story created a flood of mail from all over the country from parents in similar situations and it changed her life forever. Gemma worked together with a few of those parents and the doctors at the Shriners Hospital in Chicago, where Mike spent many days, and the result was the formation of the Osteogenesis Imperfecta Foundation which celebrates its 50th anniversary in 2020. Thousands of children worldwide, born with this rare disease, and their families have been helped over the years because of Gemma.

Some of Gemma's roles in the OI Foundation included serving as the Foundation's first Executive Director (1981-1987), serving on the

Advisory Council and the Nominating Committee for many years. She also edited *Breakthrough* (the foundations newsletter) for 14 years, providing information, inspiration, role models and support to a growing readership. Gemma was awarded the Foundation's highest honor, the Thelma Clack Lifetime Volunteer of the Year Award in 2002. Gemma told the story of raising Mike and the formation of the OI Foundation in her book "*From the Seeds of Sadness*" which was published in 2009 and can be found on Amazon.

Gemma has impacted the lives of everyone who has known her and she will be greatly missed. She is survived by her children, Cathy Bowen of Goffstown, NH, Cindy Geisman (Jay Williams) of Bastrop, TX, and Richard "Rick" Geisman (Rose) of East Hartford, CT. Gemma has eight grandchildren, Jennifer Bowen, Emily (Bowen) Blossom, Ryan Bowen, Paula (Bowen) Huntley, Sean (Samantha), Trey and Corey Geisman and Gemma "Gem" Williams. She also has seven great-grandchildren, Jacob and Caleb Shepard, Marshall Bracey, Gavin and Corbin Huntley, who lovingly called her triple G (Great Grandma Geisman) and Carson and Camden Geisman. She is also survived by two siblings Peter Marquis (Angie) of Goffstown, NH, and Robertine "Bobbie" Dryer (Chuck) of Portsmouth, NH, and a brother-in-law Jim Geisman of Horton, MI, along with many nieces and nephews who loved her dearly. Gemma is predeceased by her husband Dick and son Mike, her parents and ten siblings.

A Catholic mass and celebration of her life will be held later this year when it is safe once again to come together. Her ashes will be placed next to Dick in the Woodland Cemetery in Van Wert, Ohio. The family requests that in lieu of flowers, donations be made to The Gemma Geisman Funds at the Osteogenesis Imperfecta Foundation, 804 W Diamond Ave Suite 210. Gaithersburg MD 20878 or online at [www.oif.org](http://www.oif.org).

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## OIF National Conference Update (continued from page 1)

### VIRTUAL CONFERENCE: JULY 10-12, 2020

In place of the in-person OIF National Conference this year, we will host a Virtual Conference on July 10-12, 2020. The OIF Virtual Conference will provide live online versions of some of the most popular informational and social sessions at the biennial OIF National Conference. This online program will be free of charge for all OI community members. Check out the full OIF Virtual Conference schedule on page 4 of this issue.

#### July 10, 2020

*We're still walking and wheeling!* OI community members across the nation will come together (virtually) to participate in the OIF National Unbreakable Spirit® Walk-n-Wheel on Friday, July 10, 2020! Plan to join hundreds of OI community members to walk-n-wheel around your local park, neighborhood, or living room! Ask for support from friends, family, and neighbors; and

share how you are participating on social media! Learn more and register today at [www.oif.org/campaign/walkandwheel](http://www.oif.org/campaign/walkandwheel).

#### July 11-12, 2020

On Saturday and Sunday, the OI Foundation will host online sessions that are similar to the program you would attend at an in-person OIF National Conference. The virtual informational program (11:00am-5:00pm ET) will include topics such as the Basics of OI, Genetics, Dental, Research Updates, Pain and Fatigue, and Adult and Pediatric Health. We will also be hosting a virtual OIF Talent Show, Parents Meet & Greet, and Social Hour. Stay tuned for more information or register today at [www.oif.org/virtualconference](http://www.oif.org/virtualconference)!

Questions? Please contact the OI Foundation at [bonelink@oif.org](mailto:bonelink@oif.org) or (844)889-7579.

# We're Celebrating 50 Years of Service to the OI Community!

In 1968, Gemma Geisman wrote an article that was published in *Redbook* magazine about her son who was living with osteogenesis imperfecta. Letters started flooding her mailbox. Within months, a concerned group of parents came together to support each other and in 1970 formed the Osteogenesis Imperfecta Foundation. We owe a very special thank you to the OIF's founders and long-time volunteers.

Our founders had a vision of an organization that would help families living with OI. Today, the OIF provides information to more than 15,000 constituents each year, hosts regional and national conferences, and brings together medical professionals and researchers from around the world to help direct and advance new OI research.

We can't wait to celebrate with you! We're celebrating with a Virtual OIF Conference, new membership opportunities and new online support resources. Read more about our celebrations in this issue of *Breakthrough*!

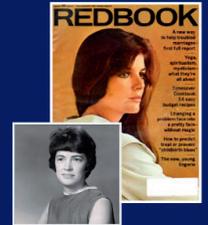
## Thank You to the OIF Virtual Conference Sponsors!



## WHERE IT ALL BEGAN

### GEMMA'S STORY

Gemma Geisman wrote an article titled *My Prison of Dreams* about her 11-year-old son who was living with osteogenesis imperfecta and the challenges they faced as a family. The article was published in *Redbook* magazine. Letters started flooding her mailbox. Within months, a concerned group of parents joined together to support each other.



### THE OIF IS BORN

A group of parents met in Chicago to make plans to organize the OI Foundation. In August, the OI Foundation was chartered as a nonprofit organization to improve the quality of life for people with OI.



### BREAKTHROUGH

In 1970, four mothers of children with OI (Gemma Geisman, Becky Keller, Renee Gardner, Midge Peck) published a quarterly newsletter that later became *Breakthrough*.



### OIF MEDICAL ADVISORY COUNCIL

The first Medical Advisory Council was elected in 1971. Dr. Harold Sofield, the man who developed the rodding procedure, was elected as Chairman.



### FIRST OIF NATIONAL CONFERENCE

In 1981, the first OI Foundation National Conference was held in Little Rock, Arkansas.



WE OWE A VERY SPECIAL THANK YOU TO THE OIF'S FOUNDERS AND LONG-TIME VOLUNTEERS.



# VIRTUAL OIF CONFERENCE

JULY 10-12, 2020

## VIRTUAL CONFERENCE PROGRAM: JULY 10-12, 2020

The OIF Virtual Conference will provide live online versions of some of the most popular informational and social sessions at the biennial OIF National Conference. This online program will be free of charge for all OI community members. To learn more, or register to attend the virtual sessions below, visit [www.oif.org/virtualconference](http://www.oif.org/virtualconference).

### Friday, July 10th

7:00pm ET

**Virtual Unbreakable Spirit® Walk-n-Wheel**  
[www.oif.org/campaign/walkandwheel](http://www.oif.org/campaign/walkandwheel)

### Saturday, July 11th

11:00am - 12:00pm ET

**Genetics/Basics of OI**

12:15 - 1:45pm ET

**Welcome/Research Update**

Sponsored by Children's Hospital & Medical Center; Omaha, NE

2:00 - 4:00pm ET

**Pediatric Panel**

Sponsored by Children's Hospital & Medical Center; Omaha, NE

2:00 - 4:00pm ET

**Adult Panel**

4:00 - 5:00pm ET

**Parents Meet and Greet**

Sponsored by Shriners Hospital for Children; Montreal, Canada

6:00 - 7:00pm ET

**Virtual OIF Talent Show**

7:30 - 9:30 pm ET

**Adults Social Hour**

### Sunday, July 12th

11:00am - 1:00pm ET

**Pain/Fatigue**

1:00 - 2:30pm ET

**Mild OI Forum**

1:15 - 2:45pm ET

**Surgical Panel for Children/Adults with OI**

Sponsored by Pega Medical

3:00 - 5:00pm ET

**Youth Forum**

3:00 - 5:00pm ET

**Women's Health Session**

3:30 - 5:00pm ET

**Dental Session**

5:30pm ET

**Closing Session**

Unable to attend the OIF Virtual Conference?  
Recordings of most sessions will be shared on the OIF website.  
Learn more at [www.oif.org/virtualconference](http://www.oif.org/virtualconference)

# Thank you for participating in National OI Awareness Week!

OI community members celebrated National OI Awareness Week 2020 (May 2-9) by participating in Virtual OI Awareness Spirit Week, sharing social media posts to promote OI awareness, and hosting virtual OI awareness events like Blue Jeans for Better Bones and Bone China Tea. Check out some of the highlights of OI Awareness Week 2020 below!

- **We reached over 206,000 people on social media throughout National OI Awareness Week.** Thank you for liking, sharing, and retweeting!
- **We received 26 official National OI Awareness Week proclamations.** Thank you to the OI community members and government officials who helped us proclaim May 2-9, 2020 as National OI Awareness Week in Alabama, Colorado, Delaware, Iowa, Kentucky, Louisiana, Maryland, Massachusetts, Mississippi, Missouri, Nebraska, New Hampshire, New Jersey, New Mexico, North Carolina, Oklahoma, Pennsylvania, Tennessee, Texas, Virginia, Washington, West Virginia, Wisconsin, Irondequoit (NY), Lower Burrell (PA), and Rochester (NY)!
- **90 OI community members created National OI Awareness Week Facebook Fundraisers.** OI Awareness Week fundraisers brought in more than 435 individual donations and raised \$19,094 on Facebook in support of the OI Foundation!
- **We raised OI awareness across the globe on Wishbone Day.** To view the OI Foundation's #SHAREforAWARENESS Wishbone Day posts, visit the OI Foundation's official Facebook page.

Raising OI awareness in your community is important year-round! For more information about hosting an OI awareness event or fundraiser, contact Christina at [cteufert@oif.org](mailto:cteufert@oif.org) or 301-947-0083.

For more information about National OI Awareness Week, visit [www.oif.org/AwarenessWeek](http://www.oif.org/AwarenessWeek).

Thank you for participating in  
**NATIONAL OI AWARENESS WEEK**

MAY 2 - 9, 2020

**NATIONAL OI AWARENESS WEEK**  
raising awareness of osteogenesis imperfecta (OI)

**26**  
OFFICIAL OI AWARENESS WEEK  
PROCLAMATIONS

**206,000**  
PEOPLE REACHED ON  
SOCIAL MEDIA

**\$19,094**  
RAISED THROUGH  
FACEBOOK FUNDRAISERS

**OI** OSTEOGENESIS IMPERFECTA FOUNDATION  
50<sup>th</sup> ANNIVERSARY

[WWW.OIF.ORG](http://WWW.OIF.ORG)

The graphic features a collage of photos: a young boy in a blue shirt, a family of three, and a young girl. It includes the OI logo and the 50th anniversary logo.

## COVID-19 Updates from the OI Foundation

During this challenging time, we at the OI Foundation will make every effort to provide you with the most up-to-date information on how the COVID-19 pandemic is affecting you and the entire OI community.

The OI Foundation, with the help of its expert partners, will continue to keep the OI community updated as more information becomes available. In the meantime, we encourage you to monitor the official CDC website [www.cdc.gov](http://www.cdc.gov) for current updates and recommendations. As a reminder, the CDC recommends the following preventive actions to help minimize the spread of respiratory diseases:

- Get your flu shot if you haven't received it yet.
- Avoid close contact with sick people.
- If you are sick, limit contact with others as much as possible. Stay home!
- Cover your nose and mouth when you cough or sneeze.
- Avoid touching your eyes, nose and mouth with unwashed hands.
- Clean and disinfect surfaces and objects that may be contaminated with germs.
- Wash your hands often with soap and water for at least 20 seconds. If soap and water are not available, use an alcohol-based hand rub with at least 60% alcohol.

If you feel sick with fever, cough or difficulty breathing and have traveled to a site listed on the CDC's website or were in close contact with someone with the coronavirus in the 14 days before you began to feel sick, seek medical care. It is recommended before you go to a doctor's office, emergency room, or urgent care facility, call ahead and tell them about your symptoms.

During this time, the OI Foundation has connected OI community members with OI experts to discuss COVID-19 related topics. To watch the recorded COVID-19 video sessions hosted by the OI Foundation, visit [www.oif.org/podcast](http://www.oif.org/podcast).

If you are an OI community member who has received a confirmed diagnosis of COVID-19 or are presumed positive by a medical professional, please contact us at [bonelink@oif.org](mailto:bonelink@oif.org). Please share if you have mild, moderate, or severe OI and any other information you feel comfortable sharing. All information we receive is critical to our medical professionals, researchers and your fellow OI community members.

As always, if you have questions please contact us at 844-889-7579 or [bonelink@oif.org](mailto:bonelink@oif.org).

# Fine Wines Strong Bones 2020

## Cheers to 50 years!

Kicking off our 50th anniversary celebrations, OI community members gathered in Naples, Florida for the 5th Annual Fine Wines Reception Naples on January 30th. Ken and Teresa Gudek, along with Andrea and Jeffrey Stewart and Jane and Jim Early, hosted the reception at the Naples Sailing & Yacht Club with over 100 attendees sampling international fine wines, participating in live and silent auctions, and testing their luck on fantastic wine themed raffles.

In February, the OI Foundation hosted its 20th annual Fine Wines Strong Bones Gala in DC. Guests gathered at the



Guests at the Fine Wines Reception in Naples, FL



OI community members came together at the Fine Wines Reception in Naples, FL

Gaylord National Resort for a gold and glitter themed evening featuring a live and silent auction, casino games, and delicious food. Together, attendees raised more than \$150,000 for the OIF with the Fund the Mission portion of the live auction raising nearly \$90,000 for the Jamie Kendall Fund for OI Adult Health. Attendees heard from OIF Medical Advisory Member Dr. Brendan Lee, OIF CEO Tracy Hart and Fine Wines Committee member Tracy Mulroy about the importance of supporting the OI Foundation as we look toward the next 50 years.

Due to the COVID-19 pandemic, the Strong Bones Gala Boston has been postponed from May 30th to **Friday, October 9th** at the Sheraton Framingham! Tickets and sponsorship opportunities are now available at [www.oif.org/strongbonesboston](http://www.oif.org/strongbonesboston). We can't wait to see you there to continue celebrating the golden anniversary of the OI Foundation with a night of glitter and gold!

Save the date as we close out the 50th anniversary celebrations at the 4th annual Boots & Bling for Better Bones on Saturday, November 7th in Houston, Texas!



Attendees at Fine Wines Strong Bones DC



Guests enjoyed casino games at Fine Wines Strong Bones DC

## Celebrate the OIF's 50th Anniversary in your Blue Jeans!

To celebrate the 50th anniversary of the OIF, we invite you to dive back into your denim collection to help us host 50 Blue Jeans for Better Bones events across the country! Blue Jeans for Better Bones is a fun and easy way to help raise money and awareness for the OI community and the work of the OIF.

This year, National Blue Jeans for Better Bones Days will take place on August 21 and December 4, 2020. Show your support and raise awareness for osteogenesis imperfecta by participating in a National Blue Jeans Day with us, or holding a Blue Jeans Day on your own date. Encourage your school, office, or community (in-person or virtually!) to get out their blue jeans – because raising awareness never goes out of style!



OIF Staff celebrating National Blue Jeans for Better Bones Day



### New this year – OIF's 50th Anniversary Photo Contest

Submit your 2020 Blue Jeans for Better Bones day photos to the OIF's 5 Decades of Denim Photo Contest for the chance to win a \$50 Old Navy gift card and OIF merchandise!

To start planning your Blue Jeans for Better Bones Day, or for more information, email Christina at [cteufert@oif.org](mailto:cteufert@oif.org) or visit [www.oif.org/bjbb](http://www.oif.org/bjbb).

## Join OI Community Members for the Virtual Unbreakable Spirit® Walk-n-Wheel!

As part of the OIF National Conference weekend, many attendees love taking part in the National Unbreakable Spirit® Walk-n-Wheel. This celebratory procession brings together old friends and new conference attendees for a fun welcome to the National Conference. This year, the OI Foundation will be taking the Unbreakable Spirit® Walk-n-Wheel virtual!

We will be joining together on a Zoom call at 7pm ET on Friday, July 10th as we all walk or wheel around our own locations\*. If you are interested in participating, visit [www.oif.org/campaign/walkandwheel](http://www.oif.org/campaign/walkandwheel). Create a team or join as an individual to set up and personalize your fundraising page. Fundraising for the OI Foundation is so important as they rely on individual donations to fund 75% of their annual budget.

Please plan to join fellow members of the OI family all across the world as we walk or wheel for OI this July. Visit [www.oif.org/campaign/walkandwheel](http://www.oif.org/campaign/walkandwheel) to sign up today!

*\*As the outbreak severity of COVID-19 varies by location, please adhere to your local rules and regulations.*



Virtual Walk-n-Wheel Co-Chair, Mark Birdwhistell, with his team in 2018

The following is a letter from OI Foundation Board President, Cameron Penn. The OIF counts on your support to help fund research, provide information and support, develop new resources, and increase public and professional awareness about OI. Please join us in celebrating the 50th anniversary of the OI Foundation and kicking-off the start of the next 50 years by making a gift to the OI Foundation today!



Dear friends and fellow members of the OI community,

I never imagined writing this letter under these circumstances. Life, for most of us, has been on hold. We're unsure of our place in the world. The sheer senselessness is far beyond most intelligence.

But, what we've already seen from the OI community during this unprecedented pandemic is incredibly positive. In the midst of searching for answers and coping with anxiety, all of you, our medical professionals, and the staff of the OI Foundation have stepped forward in ways we never thought possible. Virtual community support groups have emerged, parent groups are energized, and group video sessions have enabled the entire community to stay engaged and informed. We're pushing forward, as cliché as that sounds and as corny as it feels.



There will be modifications, there will be adjustments, and there will be challenges in the upcoming months. The OI community knows this better than anyone, and we know we're far from invincible. **As we've seen time and again over the past 50 years, we're strongest when we're together.** So, to the folks out there who want to tell us - especially those of us in high-risk populations - that getting back to normal is some sort of fantasy, we know this, too, shall pass.

Normally - there's that word again - we would be regaling you with plans for the OIF National Conference right around this time. We would be looking forward to reconnecting with hundreds of our closest friends, and we at the OI Foundation would be asking for your help, to make all of this possible. Yes, fundraising. Donations. The mission never stops.

We know that during these challenging times, it would be unrealistic to set some arbitrary fundraising goal. Individuals are hurting. Families are struggling. Under these conditions, ends don't always meet and it is hard to considering making a donation. We know that.

So here's what we would like to ask: continue reaching out, keep connecting, continue the dialogue and take part in the OI Foundation's Virtual Conference July 10-12. We're helping each other through this, we'll be back, and we'll be better, because we'll be paying more attention to each other. We'll be more aware. We'll be **#strongertogether**.

**For those of you who are able and would like to contribute to the OIF's mission during this time of extreme need, you'll be helping us face the unique challenges that come with this climate.** The need to support our community hasn't evaporated, it has doubled. We would greatly appreciate your continued support, even in the smallest way. To contribute, go to [www.oif.org/donate](http://www.oif.org/donate) or return the enclosed envelope with your special gift. More than ever, a single dollar goes a long way. Especially because thanks to one generous donor, we will match the first \$10,000 raised through June 15th.

Someday, we won't be too scared to join together again. To hug. To high-five. To embrace. Gatherings of family and friends will begin to return - even if we are still struggling or still a bit unsure. We'll do it, because it means so much. Those small, but powerful moments safeguard our memories. They are the way we celebrate being alive.

Even though the world has been transformed, and "getting back to normal" means something different now, that's what we'll do, no matter who or where we are. Because that's what living is.

Until we can once again gather on a grand scale - mark July 8-11, 2021 on your calendars now for the re-scheduled OIF National Conference in Omaha, NE. All of us on the OIF staff and board of directors hope you, your families, friends, and co-workers are and will remain in the best of health. We encourage you to reach out to the OI Foundation with any questions or concerns you may have.

Warm Regards,

A handwritten signature in black ink, appearing to read 'Cameron Penn', written in a cursive style.

Cameron Penn  
President, OIF Board of Directors  
[cameron@heyguymedia.com](mailto:cameron@heyguymedia.com)



## Support the next 50 years of the OI Foundation – Participate in Bone China Tea

### A Message from Bone China Tea Chair Susie Wilson

*As we mark the 50th anniversary of the OI Foundation we are so incredibly grateful of how far we have come and where we are going as an organization. When I was born in 1968 there was no OI Foundation, Internet, Support Groups or a way for anyone to connect with each other. Fifty years later, the OI Foundation is staffed with 10 people whose mission is to “improve the quality of life for those living with osteogenesis imperfecta through research, education, awareness and mutual support.” Support groups have been formed throughout the United States. National and Regional conferences have been created and continue to grow with each event.*

*So much has transpired over the past 50 years but none of these programs can continue without individual volunteer fundraisers. You may feel intimidated when it comes to fundraising, but there are many things you can do to get started!*

*Bone China Tea is one of the easiest fundraisers you can participate in to help raise money for the OI Foundation. It is a phantom event, that can be held on the date that works best for you!*

*What is a phantom event? Instead of purchasing a ticket to attend an in-person event, you are asked to stay at home and have a cup of tea and donate the money you would have spent on attending a fundraising event to the OI Foundation. You can participate in two ways: The first way is by asking the OI Foundation for invitations, which will be sent to you complete with a tea bag and an RSVP card, that you would then send to your family and friends. In my invitations, I include a personal update on how OI has affected me that past year. This is a great way to update family and friends on how OI affects you or your loved one. It is also a way to promote OI awareness and have friends, family, and co-workers learn about OI. The second way is by creating an online Bone China Tea webpage, sending emails out to your friends, family and co-workers and sharing on social media.*

*In honor of the OI Foundation's 50th anniversary, I invite you to participate in Bone China Tea and help continue to build our OI community for another 50 years!*

Susie Wilson  
Bone China Tea Chair  
Co-Chair of the Florida OI Support Group



# OI Community Member Spotlight: Angelo Collazo

Ten years ago, my wife and I lost our first daughter, Alle Shea Collazo, to the rare brittle bone disease, osteogenesis imperfecta (OI). At birth, Alle had broken ribs, an arm, legs, and a wrist, and her skull had many fractures. Alle graced our lives for only five weeks. The first time we were able to hold Alle without pillows and cushions between us was the day she passed away. On that day, we promised Alle Shea that we will keep her fight alive. With that promise, The Alle Shea Project was born. With the help of the OI Foundation, we held our first Walk in August of 2009. This was going to be a one-time event, but we had many people asking about the next one that we decided to do another. This led to more than twenty fundraising and awareness events that we have held.

We held five Walk-n-Wheels from 2009 to 2013, and in 2014 we created the OI Love Dessert & Dance fundraiser (2014 to present). This event features dessert samples, a baking contest, music, raffles, karaoke, and dessert related vendors. Every year, on Alle's birthday we have a special fundraiser at one of our local Uno Pizzeria & Grill restaurants. We fundraise and raise OI awareness in many different ways: we have hosted comedy shows and loose change fundraisers, planned Blue Jeans for Better Bones fundraisers, created awareness videos, planned group nights at local sports games, and participated in TV & radio interviews. Each year we submit a proclamation request to the Town of Irondequoit, NY; the City of Rochester, NY; and the State of New York to proclaim National OI Awareness Week.

In February of 2015, we started a new program called *OI Care for You*. We send care packages that include small stuffed animals



Kim, Angelo, and Alle Shea

(we call them Snuggle Buddies), stickers, coloring books, and other ladybug themed novelties to anyone that requests one for a child with OI. These packages are sent free of charge. Items are provided by us or are donated to this special program.

The idea behind the *OI Care for You* program is that everyone should have a little something to hold, to snuggle, and to help bring comfort and a smile during difficult times. Anyone, anywhere in the world who knows of a child with OI that had a recent break, surgery, or treatment, is welcome to request an "OI Care for You" Snuggle Buddy care package. To date, we have sent over 187 packages to OI children in more than forty states and ten countries.



Kim and Angelo Collazo raising OI awareness in their community in memory of their daughter Alle Shea



Angelo, Ella, and Kim Collazo



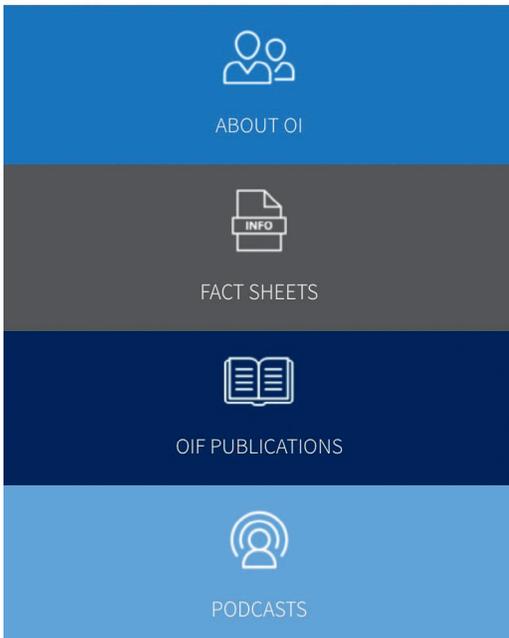
## Celebrating 50 Years of the OIF Information Center

Fifty years ago, a small group of parents made it their mission to bring information and support to families with OI.

Today, the OI Foundation Information Center lives both online and within the OI Foundation national office. The Information Center receives nearly 11,000 requests for information each year from parents, adults, medical and legal professionals, students, and caregivers. If you have an OI-related question, feel free to call or email us! We are available as a cost-free resource for anyone affected by OI. The online Information Center allows an individual to access medically verified information including digital versions of fact sheets, OIF Publications, podcasts, and other resources.

You can also access the OIF Information Center by phone or email. Our Health Educator is available to connect you to information and support resources. The OIF also maintains Clinic and Physician Directories to help families living with OI locate medical care in their area.

*We are here to help! Please visit the online OIF Information Center at [www.oif.org/informationcenter](http://www.oif.org/informationcenter) or contact us at [bonelink@oif.org](mailto:bonelink@oif.org) or 301-947-0083.*



## Empowering the Adult OI Community

In 2016, a group of dedicated OIF volunteers, led by former board member and longtime volunteer Tracy Mulroy, established an initiative to honor the life of Jamie Kendall, former OIF board president and tireless advocate for people with OI. The goal of the Jamie Kendall Fund, a program of the OIF's Adult Health Initiative is to identify the health implications of aging with OI and disseminate the findings to both individuals living with OI and their medical providers. Jamie was passionate about empowering the adult OI community in the areas of education, employment and their unique health concerns. She encouraged adults with OI to push beyond themselves and plan for a health future.



Jamie Kendall

One of the key projects of the Jamie Kendall Fund was to fund a clinical study focusing on pulmonary issues and the risk of early death from poor lung function or poor respiratory function. Dr. Cathleen Raggio from Hospital for Special Surgery was awarded the inaugural Jamie Kendall Fund Clinical Research Grant to focus on pulmonary issues of adults with OI. The study is

entering its second full year of funding and is pleased to report to the OI community the progress made thus far. Highlights of the pulmonary study to date include:

- Established partnership with Dr. Robert Sandhaus, Pulmonologist at National Jewish Health in Denver, CO.
- Preliminary data shows that there is an intrinsic lung pathology in people with OI that is not related to the degree of scoliosis.
- Currently there are 41 adults enrolled in the study.
- A paper containing preliminary results with 30 adults has recently been accepted by a scientific journal.
- Next steps include increasing enrollment to 50 patients, performing lung bronchoscopies to better delineate why people are having bronchial wall thickening so a treatment can be suggested and continue collaboration with National Institutes of Health on genetic markers in OI lungs in animal models of OI.

Dr. Raggio and Dr. Sandhaus will continue their work and thank the donors to the Jamie Kendall Fund for their support.

Moving forward, the Jamie Kendall Fund will continue to fund innovative programs and research studies that will provide greater knowledge of OI-related health issues facing adults living with OI.



# Resources for Voters with OI

As the Presidential Primaries continue and the 2020 Election nears, the OIF wants to support everyone's right to vote. According to federal law and the American Civil

Liberties Union (ACLU), **all voters with disabilities, including those with OI, may obtain assistance in voting from a person of their choice, as long as it is not their employer or representative of their union. In addition, all federal election polling locations must be accessible, or they must provide alternative means for casting a ballot on the day of the election.** Sadly, this is not the reality for many. Over 60% of polling sites researched in the 2016 Election had some type of potential impediments to vote.

To help navigate potential barriers, the OIF has compiled a short checklist with resources to help ensure your vote counts. Since laws and procedures vary so much by state, please be sure to check with your local and state election offices.

## BEFORE YOU VOTE

1. **Check if you are registered to vote.** Visit [www.vote.org](http://www.vote.org) to check your voter registration status, or to register. This is a free service.
2. **Research your state's voting requirements, polling locations, and accessibility.** Important topics that you may want to research can include the different ways to vote, polling site locations, their voting machine and space accessibility, and parking. Research where, when, and how you can vote by finding your state's election website at [www.usa.gov/election-office](http://www.usa.gov/election-office).

3. **Feel like you need more help?** Look up your state's Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP). These agencies may be able to provide more information and resources about voting for people with disabilities in your state. A full list of those organizations can be found at [www.ndrn.org/about/ndrn-member-agencies/](http://www.ndrn.org/about/ndrn-member-agencies/).

## GETTING TO YOUR POLLING PLACE

1. **Need a ride?** Carpool Vote ([www.carpoolvote.com/](http://www.carpoolvote.com/)) has offered free rides to the polls, and may have some accessible vehicles available. Also, Uber offered Election Day promotions in the past, and Lyft has announced a similar initiative for 2020.

## AT THE POLLING SITE

1. If poll workers are unable to find your name, you may ask for a provisional ballot.
2. Want to report a problem? There are multiple hotlines you can reach out to if you wish to report a problem.
  - a. The Election Protection Coalition has a national hotline at 866-OUR-VOTE.
  - b. Your state P&A may have its own separate hotline as well. A list of state P&A organizations can be found at [www.ndrn.org/about/ndrn-member-agencies/](http://www.ndrn.org/about/ndrn-member-agencies/).
  - c. The Arc of the United States has created a Voter Support Service website that is mobile friendly. You can report an issue at your polling place there. [www.vote.thearc.org/ask/](http://www.vote.thearc.org/ask/).

# Join the OIF Book Club!

Introducing the OI Foundation's newest fundraising program, the *OIF Book Club* reading program! The *OIF Book Club* is for students and readers alike who enjoy the company of a good book and want to help support the work of the OIF. Your participation directly supports the OIF's mission to improve the quality of life for those living with osteogenesis imperfecta through research, education, awareness and mutual support. The more you read, the more money you raise, and the more prizes you can win! Once your fundraiser has ended, prizes will be mailed to your home. Visit



[www.oif.org/campaign/OIFBookClub](http://www.oif.org/campaign/OIFBookClub) for more information!

Join the **OIF Book Club** Reading Program

Register online to get started! [www.OIF.org/campaign/OIFBookClub](http://www.OIF.org/campaign/OIFBookClub)

Earn these great prizes!

<b>\$30</b> Thank You for your support! UNBREAKABLE SPIRIT® WRISTBAND	<b>\$20</b> A COPY OF JASON'S FIRST DAY OR EMILY'S FIRST DAY WITH OIF BOOK CLUB BOOKPLATE	<b>Free!</b> OFFICIAL PARTICIPATION CERTIFICATE
<b>\$40</b> UNBREAKABLE SPIRIT® SUNGLASSES	<b>\$100</b> OIF BOOK CLUB READING MEDAL	<b>\$50</b> OIF SMILEY STRESS BALL
<b>\$75</b> UNBREAKABLE SPIRIT® WATER BOTTLE	<b>\$150</b> A COPY OF MISSY BY ANDERSON DYKE WITH OIF BOOKPLATE	<b>\$200</b> MINI 50TH ANNIVERSARY GOLDIE BEAR



## OI Foundation's PCOR Project Update

### Locate Medical Care with the OI Directories

The OI Foundation has recognized that one of the difficulties that many OI community members face is finding a team of medical professionals who are familiar with working with OI.

Since 2005, we have tried to make locating medical care easier by providing the community with a directory of over 50 U.S. based OI clinics listed by state. The OIF Clinic Directory is featured on our website ([www.oif.org/clinicdirectory](http://www.oif.org/clinicdirectory)), and aims to provide you and your family with accurate, verified, and easily accessible information to assist you in locating dependable and multidisciplinary medical care. The directory provides information including the hospital and clinic names, contact information, as well as the services each clinic offers.

In addition to the Clinic Directory, if you are looking for a specific type of physician, the OIF also maintains a Physician Referral List that can be accessed by calling or e-mailing the OIF office at [bonelink@oif.org](mailto:bonelink@oif.org) or (301) 947-0083.

*Do you know of a clinic or a physician that works with people with OI that you don't see on our lists? Help us provide the most up-to-date information to the community by letting us know! Please email or call us with the name of the physician or clinic at [bonelink@oif.org](mailto:bonelink@oif.org) or (301) 947-0083.*

Last summer, the OIF was approved for a funding award by the Eugene Washington PCORI Engagement Awards (Engagement Awards) program, an initiative of the Patient-Centered Outcomes Research Institute (PCORI). The project represents the OI Foundation's first step to engage the entire OI community in defining the critical aspects of living with OI across the lifespan. The goal is to develop a coalition of community and medical professionals who will direct and encourage new OI research. The project is underway, and we're excited to give you an update of where we are so far:

Since June of 2019, we have established our project's committees, which consists of members of the OI community, as well as experts in the field of Patient-Centered Outcomes Research to help guide our project. We also have officially launched the project on social media, as well as at our Regional Conferences in Sacramento, Atlanta, and Phoenix. A dedicated page for this project is available on the OI Foundation's website ([www.oif.org/pcor](http://www.oif.org/pcor)), where you can follow the work we're doing, or read more about Patient-Centered Outcomes Research.

**How Can You Get Involved?** First, make sure that you're registered for the OI Registry! As the project goes on, we plan to use the OI registry as the platform for gathering insights from the community, allowing you to really tell us your story.

If you have any questions about the project, please contact us at [bonelink@oif.org](mailto:bonelink@oif.org).

### OIF Regional Conference: Phoenix, Arizona

OI community members traveled from across Arizona and the Southwest for the opportunity to speak with OI experts and meet other OI community members at the OIF Regional Conference in Phoenix, AZ, on March 7, 2020. Locally based medical professionals and OIF Medical Advisory Council members led sessions ranging from *Basics of Osteogenesis Imperfecta* to *Dental Health and Pain Management*. In the afternoon, attendees shared their experiences in breakout sessions aimed at promoting independence for young people and managing adult health.

The OIF would like to thank Dr. Pamela Smith and the Phoenix Children's Hospital for hosting the event, and all of the speakers and attendees who made this event possible. We also want to thank OIF Medical Advisory Council Members, Dr. Laura Tosi and Dr. Cathleen Raggio, for traveling to Phoenix to share their expertise with the OI community members in Arizona.



Attendees at the OIF Regional Conference in Phoenix, AZ



Attendees at the OIF Regional Conference raise their hands if it is their first OIF event

# Join Fellow Members of the OI Community at an Upcoming Event



With just 50,000 people affected by osteogenesis imperfecta in the United States, coming together with others in your area to support the OI Foundation is vital. The OI Foundation is very lucky to have a large number of volunteers around the country who hold fundraising events, awareness events and support group meetings.

Due to the COVID-19 pandemic, many events from the spring and early summer are being converted to virtual events or postponed to the fall. Below are some of the events being held in the upcoming months.

Try to attend one near you and share our Unbreakable Spirit®!

## July

- July 10** Virtual Unbreakable Spirit® Walk-n-Wheel – Your hometown!
- July 10–12** OIF Virtual Conference
- July 21** Dogfish Head Alehouse Proceeds Day for OI – Gaithersburg, MD

## August

- August 1** **\*New Date\*** The Alle Shea Project's Uno Pizzeria & Grill Dough-Raiser – Irondequoit, NY
- August 9** OI Carnival – Whitehall, PA
- August 10** OI Golf Classic – Atkinson, NH
- August 22** **\*New Date\*** 3rd annual Unbreakable Spirit® Dance – Buzzards Bay, MA

## October

- October 9** **\*New Date\*** 4th annual Strong Bones Gala, Boston – Framingham, MA

## November

- November 7** 4th annual Boots & Bling for Better Bones – Houston, TX

Visit the events calendar at [www.oif.org/events](http://www.oif.org/events) for up-to-date details.

Are you interested in holding awareness or fundraising events for the OI Foundation? Contact [events@oif.org](mailto:events@oif.org) for more information today!

### Follow us on social media!



**Osteogenesis Imperfecta Foundation**



**@OIFoundation**



**@OIFoundation**

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JOIN THE OI FOUNDATION'S

# 1970 SOCIETY

## CELEBRATE THE OIF'S 50TH ANNIVERSARY

*Founded in 1970, the OI Foundation has provided information and resources to families living with osteogenesis imperfecta for the past 50 years. Generous support from donors like you helps the OIF continue to move forward in our mission to improve the quality of life for those living with OI through research, education, awareness, and mutual support.*

Members who give \$1,000 this year will become part of the **1970 Society** commemorating the OIF's 50th anniversary. Members receive a limited edition 50th anniversary lapel pin and a miniature Goldie 50th anniversary teddy bear.

OSTEOGENESIS  
IMPERFECTA  
**OI**  
FOUNDATION

*Unbreakable Spirit®*

50<sup>TH</sup> ANNIVERSARY