

2020 ANNUAL REPORT

OSTEOGENESIS IMPERFECTA

FOUNDATION www.OIF.org



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FOU

Board of Directors

PRESIDENT Cameron R. Penn,

Manhattan Beach, CA

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SECRETARY Sharon Mutnick, MBA, Atlanta, GA

MEDICAL ADVISORY COUNCIL CHAIR

Francis Glorieux, OC, MD, PhD, Shriners Hospitals for Children - Canada Montreal, QC, Canada

MEMBERS

Michele Burka, MBA, Tamarac, FL Brett L. Eisenberg, Bronx, NY Kenneth D. Finkel, Indianapolis, IN Eric Gould, Miami Beach, FL Joe Hall, Columbia, SC Tracy L. Mulroy, JD, Bethesda, MD Wendy E. Sacks, New York, NY Michael Sheridan, Downers Grove, IL Laura Tosi, MD, Washington, DC

Children's National Medical

S. Jacinta Whyte, Toronto, ON

The mission of the OI Foundation is to improve the quality of life for those living with osteogenesis imperfecta through research, education, awareness and mutual support.

A Message From the President

"It has become increasingly apparent that no year in the storied history of the OIF may have a greater, broader impact than 2020."

I wrote that. A year ago. Seems like an eternity. Sounds negative now but it was never meant to carry that connotation, only a reflection of the uncertainty we were all facing. The OIF,



like the entire OI community and the rest of the world, was at a crossroads. While we were kicking off the OIF's golden anniversary, the experts were marking the so-called 'peak of the pandemic.' Much has changed in the intervening year and a great deal of uncertainty remains, but we've learned so much, especially from each other.

I don't think any of us knew what we were dealing with at the time, much less when it might end. But as a Foundation and a community, we knew we had to ascertain the knowledge to properly address individual and collective concerns, and we knew we needed to invest in outreach in a manner and capacity like never before. If not, the very future of the OIF was at stake. I'll be brutally honest: we were worried. But as board presidents before me have noted time and again, this community is a collection of miracle workers, selfless beyond compare and generous to a fault. As I write this now, I'm proud to say that the OIF is not only better positioned to serve the needs of the OI community and uphold our mission, but thanks to each of you, our medical professionals, our Board of Directors and the entire staff at the OIF, we were able to turn that notion of uncertainty on its head.

From a support standpoint, each of you played pivotal roles in re-shaping the OIF into what it is today. Part of our commitment to re-imagining our role in the OI community was listening to each of you. We asked for your voice and we got it, in droves. Out of your feedback emerged community town halls and focus groups, along with virtual get-togethers and fundraisers. Late last year, the Geisman Family and the OIF launched Gemma's Corner on YouTube. This collection of first-person stories chronicles personal journeys and successes from OI community members.

From a research perspective, we promised to change our approach and transparency when it comes to information, and we have. During OI Awareness Week 2021, we're launching a new "discovery series" featuring some of our most prominent medical professionals. We want you to be the first to know about new trends, discoveries on the horizon and the latest research. Throughout the year, we'll be hosting live town halls with some of OI's top investigators, like Dr. Brendan Lee, Dr. Deborah Krakow, Dr. Eric Rush and many others. We'll have open, candid conversations covering the most-requested topics, including pregnancy, pulmonary and dental. Recently, Dr. Laura Tosi shared eye-opening results from the first of two COVID-19 surveys commissioned by her tireless team at Children's National in Washington DC.

Between now and July 2022, we'll hold back-to-back national conferences for a total of three in three years. In addition to the customary conference topics, we'll be devoting a significant amount of time to address topical issues, including COVID-19. In 2022, we plan to gather again in-person, this time at the JW Marriott Grande Lakes Resort in Orlando FL. Stay tuned for more details as they become available.

A year removed from that quote, we now have a much better idea how great and how broad the impact on the OIF would become. And while the uncertainty wasn't unfounded, we also know the impact was unexpectedly positive. For that, we can only thank <u>you</u>!

Cameron Penn President, OIF Board of Directors cameron@heyguymedia.com

Medical Advisory Council

Francis Glorieux, OC, MD, PhD -Chairman

- Principal Investigator, Brittle Bone Disorders Consortium site in Montreal, Qc, Canada
- Principal Investigator on the landmark 1998 study on using bisphosphonates to treat children with Ol; author of the OI Foundation booklet, Guide to OI for Pediatricians and Primary Care Physicians, and senior editor of Pediatric Bone: Biology & Diseases

Peter Byers, MD

- University of Washington School of Medicine, and University of Washington School of Dentistry, Seattle, WA
- Genetic Medicine Clinic, University of Washington Medical Center, Seattle, WA
- Recipient of March of Dimes/ Colonel Harland Sanders Award for lifetime achievement in the field of genetic sciences

Hollis Chaney, MD

- The George Washington University School of Medicine and Health Sciences, Washington, DC
- Children's National Health System, Washington, DC, as Vice Chair of the Division of Pulmonary Medicine

Paul Esposito, MD

- Clinical Service Chief, Pediatric Orthopedic Surgery Surgeon, Children's Hospital and Medical Center, Omaha, NE
- Professor of Orthopaedic Surgery and Pediatrics, University of NE Medical Center, Omaha, NE
- Co-Director for The OI Clinic at Children's Hospital and Medical Center in Omaha

MEDICAL ADVISORY COUNCIL (continued)

Deborah Krakow, MD

- UCLA, David Geffen School of Medicine, Los Angeles, CA
- American Board of Medical Genetics board member
- American College of Obstetrics and Gynecology policy committee on Genetics
- Principal Investigator, Brittle Bone Disorders Consortium site in Los Angeles, CA

Richard W. Kruse, DO, MBA

- Professor of Orthopaedic Surgery Thomas Jefferson University College of Medicine in Philadelphia, PA and the Uniformed Services University School of Medicine in Bethesda, MD
- Vice Chair Department of Orthopedics and Chief of the Orthopedic Trauma Service at Nemours/Alfred I. duPont Hospital for Children in Wilmington, DE
- Co-Director for the multidisciplinary OI program at Nemours/Alfred I. duPont Hospital for Children in Wilmington, DE

Brendan Lee, MD, PhD

- Baylor College of Medicine, Houston, TX
- Principal Investigator, Brittle Bone Disorders Consortium
- Dr. Lee is an elected member of the National Academy of Medicine

Joan Marini, MD, PhD

- Chief, Bone and Extracellular Matrix Branch, National Institute of Child Health and Human Development (NICHD), National Institutes of Health, Bethesda, MD
- Director of Translational Research
 Program on OI at NICHD
- Principal Investigator, NICHD Pediatric Research Program
- Twice awarded the National Institutes of Health Director's Award for her research on OI

Regional Conferences

Since its launch in 2015, the OIF's Regional Conference program, Uniting Unbreakable Spirits, has reached more than 1,500 members of the OI community, half of whom had never attended an OI event before. In October 2019 and March 2020, the OIF hosted regional conference in Wilmington, Delaware, and Phoenix, Arizona. Since then, we have also hosted virtual regional conferences for the Washington, DC area and New England. These one-day meetings provide a unique opportunity to meet fellow members of the OI community and hear from OI experts in your area.





COVID-19 Response

During this challenging time, the OI Foundation has made every effort to provide individuals with the most up-todate information on how the COVID-19 crisis may affect the OI community. The OI Foundation has connected OI community members with OI experts to discuss COVID-19 related topics in virtual sessions, as well as virtual support group meetings held on Zoom. Topics included: Information on Covid-19, Mental Health and Wellness, Orthopedic Perspectives, Nutrition, and COVID-19 Vaccine Information.

The OI Foundation is making every effort to provide the most up-to-date information about the COVID-19 pandemic for the OI community. The COVID-19 Toolkit, one of the OIF's newest resources, provides information and resources related to the COVID-19 pandemic specific to the OI community. To view the COVID-19 toolkit, please visit **www.oif.org/category/covid19**.

COVID-19 Video Resources

Throughout the COVID-19 pandemic, the OI Foundation has hosted a series of video sessions to connect OI community members with experts to discuss COVID-19 related topics. Session topics have included Medical Updates, Orthopedic Perspectives, Mental Health and Self-Care Strategies, Healthy Eating, Employment Accommodations, and COVID-19 Vaccine. To watch the recordings of these sessions, visit the OIF podcast webpage at www.oif.org/podcast.



MEDICAL ADVISORY COUNCIL (continued)

Sandesh C.S. Nagamani, MD

- Associate Professor in the Departments of Molecular and Human Genetics and Internal Medicine at Baylor College of Medicine
- Clinical geneticist providing clinical care for adult patients with a wide variety of heritable conditions including OI
- Investigator, Brittle Bone Disorders
 Consortium (BBDC)

Cathleen Raggio, MD

- Hospital for Special Surgery, New York, NY, Orthopedic Surgeon
- Co-Director of the Kathryn O.
 and Alan C. Greenberg Center for Skeletal Dysplasias
- Principal Investigator, Brittle Bone Disorders Consortium site in
 New York, NY

Frank Rauch, MD

- Canadian Shriners Hospitals for Children, and McGill University Faculty of Medicine, Montreal, Quebec, Canada
- Director, Biomedical Laboratory, Shriners Hospitals for Children, Montreal, Quebec
- Principal Investigator, Brittle Bone Disorders Consortium site in Montreal Qc, Canada

David Rowe, MD

- University of Connecticut Health Center, Farmington, CT
- Director for Regenerative Medicine and Skeletal Development, University of Connecticut

Sandy Sandhaus, MD, PhD

- University of Colorado School of Medicine, and National Jewish Health, Denver, CO
- Clinical Director at the Alpha-1 Foundation, Denver. CO
- Medical Director and Executive Vice President of AlphaNet
- Dr. Sandhaus applies his experience with internal medicine, pulmonary disease, critical care medicine and the biopharmaceutical industry to the study of lung disease

MEDICAL ADVISORY COUNCIL (continued)

Jay Shapiro, MD

- Dr. Shapiro is Consultant to the Endocrine and Diabetes Dept. at the Walter Reed National Military Medical Center, Bethesda, MD
- Endocrinologist experienced in the treatment of genetic and metabolic bone disorders in children and adults
- Former, Director of the Bone and Osteogenesis Imperfecta Department, Kennedy Krieger Institute, Baltimore, MD. Professor in Dept. Physical Medicine and Rehabilitation Johns Hopkins School of Medicine
- Dr. Shapiro is the Editor-in-Chief of the 2014 textbook, Osteogenesis Imperfecta: A Translational Approach to Brittle Bone Disease (Elsevier Publishers).

Peter Smith, MD

- Pediatric Orthopaedic Surgeon at Shriners Hospital for Children, Chicago
- Professor, Orthopaedic Surgery, Rush University Medical Center
- Director, Osteogenesis Imperfecta Clinic, Shriners Hospital for Children, Chicago
- Principal Investigator, Brittle Bone Disorders Consortium site in Chicago
- Dr. Smith has visited China, India and several countries in South American to train physicians in surgical techniques related to OI
- Co-Editor of the 2015 textbook, Transitional Care in Osteogenesis Imperfecta: Advances in Biology, Technology, and Clinical Practice(Shriners Hospitals for Children - Chicago, Publishers)

Reid Sutton, MD

- Texas Children's Hospital Skeletal Dysplasia Clinic and Baylor College of Medicine Department of Molecular and Human Genetics, Houston, TX
- Director of the Medical Genetics
 Residency Program
- Medical Director of the Biochemical Genetics Diagnostic Laboratory
- Administrative Director and Principal Investigator, Brittle Bone Disorders Consortium Rare Disease Clinical Research Center, Baylor College of Medicine and Texas Children's Hospital, Houston, TX

Awareness and Education

On May 2-9, 2020, the OI Foundation organized its 11th annual National OI Awareness Week. OI Awareness Week was proclaimed in 26 states across the country. Volunteers participated in virtual fundraising events such as Bone China Tea and the OIF Art Auction. Throughout the week, more than 200,000 individuals were reached on social media and 90 OI community members created Facebook fundraisers to raise nearly \$20,000 to help support the work of the OI Foundation.



OIF Virtual Conference

After careful consideration, the OIF's Board of Directors and OIF Staff made the difficult decision to pivot the planned 2020 OIF National Conference to a 2-day virtual conference. Although we were disappointed to not be able to come together in person, the health and safety of the OI community comes first. The OIF Virtual Conference provided live online versions of 15 of the most popular informational and social sessions at the OIF National Conference to more than 900 participants from across the U.S., Canada, Europe, Africa and Australia – all free of charge. As a way to kick-off the OIF's Virtual Conference weekend, we held a Virtual Unbreakable Spirit[®] Walk-n-Wheel chaired by Mark Birdwhistell, Stephanie Greenwood and Dr. Maegen Wallace.

MEDICAL ADVISORY COUNCIL (continued)

Laura Tosi, MD

- Children's National Health System, George Washington University
 School of Medicine and Health
 Sciences, Washington, DC
- Orthopedic Surgeon
- Principal Investigator, Children's Research Institute (CRI), Center for Genetic Medicine Research (CGMR), Children's National Medical Center, Washington, DC
- OI Foundation Board of Governor's Representative to the National Bone Health Alliance
- Chair, Rare Bone Disease Working Group – NBHA—representing the OI Foundation
- Principal Investigator, Brittle Bone Disorders Consortium site in Washington, DC

David Vernick, MD

- Harvard Medical School, Boston, MA
- Surgeon in Otolaryngology at Massachusetts Eye and Ear Infirmary, Beth Israel Deaconess Medical Center, Brigham and Women's Hospital, and Children's Hospital, Boston, MA

Matthew Warman, MD

- Director of Orthopedic Research Laboratories, Department of Orthopaedic Surgery, Boston Children's Hospital, Boston, MA
- Professor, Departments of Orthopaedic Surgery and Genetics, Harvard Medical School, Boston, MA

Michael Whyte, MD

- Washington University School of Medicine, St. Louis, MO
- Shriners Hospitals for Children, and Barnes-Jewish Hospital, St. Louis, MO
- Medical-Scientific Director, Center for Metabolic Bone Disease and Molecular Research, Shriners Hospitals for Children, St. Louis, MO

2020 Members

Waheeda Afridi Michael Ahern Gunner Albitre Tillie Allen Paul Andrews Mohammad Aslam Cindy Assmann Wanda Bachman Dee Baraw Jeffrey & Cynthia Barnett David & Marita Barth Don & Chris Baumann Rebecca Beall Di Sabato, Esq. **Michael Bellas** Anthony & Jennifer Benish Ellen Benish Jerry & Patricia Bennett Jo Ann Berkenbush Norman & Ethel Berman James & Donna Bernie Robert Bernstein Joan Berry Steven Biagini Carolyn Bickham Krystal Bickham Bonnie Bolden Linda Boryczka Cathy Bowen John & Nancy Braitmayer Karen Braitmayer & David Erskine John & Denise Brill Edward & Ruth Brosh Faye Bross Nathaniel & Kim Brost Lucinda Brown Patricia & Steve Bruce Patricia Bruno

Rare Bone Disorder and OI TeleECHO Sessions

The OI Foundation and Rare Bone Disease Alliance's monthly Rare Bone Disease TeleECHO Clinics have been gaining popularity in the medical community both in the U.S. and internationally. Thanks to this success, the OIF launched the first OI focused TeleECHO series this year. This virtual continuing medical education platform will increase access to expert medical knowledge for participating physicians and medical professionals. This program will connect practitioners across the globe for monthly sessions that will include brief presentations and real-world case presentations focused solely on osteogenesis imperfecta. The OI TeleECHO Series will improve the ability of medical professionals to treat patients with OI.



Eugene Washington PCORI Engagement Award

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 uses the OI Registry as one of several platforms for gathering insights from the community, allowing you to really tell us your story. If you are interested in being involved in shaping the future of OI research, make sure that you are signed up for the OI Registry!

OIF Information Center

This past year, OIF staff responded to more than 11,000 direct inquiries for medically verified information, and an average of 40,000 people used the OIF website each month. Topics range from medical issues such as genetics, diagnosis, and treatments to daily living strategies such as school and employment. Educational materials are available in print and electronically through the OIF website.

2020 MEMBERS (continued)

Michael & Tracy Bryan Barbara Burke Terry & Carolyn Burke Guillermo & Nelly Cabacungan, Jr. Rebecca Ann Callighan Samuela Camelliti Don Carolan & Madeline McLaughlin Mary Jane Cera Philip Chaikin, PharmD, MD Paul & Elsa Chase Yuka Chau Chris & Jennifer Chilton Sarah Ciaccia & Robert Morgan Christine Cino Ashleigh Clack Howard & Joan Coleman Clarence & Wilada Coleman Terence & Carmen Connors Elyse Constantin Charles Cook Peter and Philomena Coppa Thomas & Kristy Corkran Bill & Michelle Cramer Cliff & Terri Creek Patsy Cross Despina Cusulos Joe & Janice Daniel William Danner Ken & Melissa Davert Steve & Leann Davidson Monica Dean Joshua Dean Brenda & Duane DeBlied Julia Delgado Donna Derby John & Lori DeRosa Gail Desmarais Ken & Diane Dietteri

2020 MEMBERS (continued)

Sean & Jamie DiGeorge Peq Dombro Colin Donnaruma Michelle Duprey, Esq. Earl & Sarah Dyke Meredith Earls Fran Ely William Eslinger Robert Henry & Roberta Esposito Larry & Barbara Estrada **Robert & Claudia Faherty** Myrtle B. Fantroy **Douglas Faraci** Jeff & Michelle Flitcroft **Robert & Juliet Carter Franzen** Jeanne Franzone MD Ralph & Janice Freeman Bernice Freudensprung **Rachel Fritz** Carl & Elizabeth Gaglio Don & Renee Gardner Abigail Garfield Dorothy Gay Ann Marie Geiger Mark & Meredith Goldberg Naomi Goldstein John & Paula Goodrich III John & Barbara Goodrich Jr. **Corinne Gottman** Paul & Dina Granger Virginia Greene Stephanie Greenwood Peggy Grigg Charlene Grimo Juanita Gruenloh Charla Gualano Stephen Gudek Sr. Donald & Barbara Hagy Anat Haimovici

Impact Grants

In partnership with the Children's Brittle Bone Foundation, the Jeanie Coleman Impact Grant program was designed and established to provide funding for items that will significantly improve the quality of life for a person who has OI. This year, the OIF was able to fund more than \$100,000 of items and services including travel for surgery, hearing aids, new wheelchairs and physical therapy.

Navigating a New Diagnosis: A Toolkit for Parents and Medical Professionals

This tool kit, sponsored in part by a donation from Minnesota Neonatal Physicians in memory of Michael Johnston – a long time OIF volunteer and past board member – covers topics including diagnosis of OI, types of OI, caring for a newborn with OI, and information to share with your doctor. The *Navigating a New Diagnosis Toolkit* is available online and in print for OI community members, medical professionals, OI clinics, and bone health programs.



A TOOL KIT FOR PARENTS AND MEDICAL PROFESSIONALS

Social Networking

The OI Foundation manages three official social networking sites: the OIF Facebook Page – followed by 13,274 Facebook users; the OI Foundation Twitter page (@OIFoundation) – followed by 2,577 Twitter users, and the OIF Instagram page (@oifoundation) – followed by 1,215 Instagram users. This year the OI Foundation also launched the OIF YouTube channel highlighting virtual information sessions, COVID-19 community calls, and fundraising event recordings. A new series was created in honor of OI Foundation founder, Gemma Geisman, to share stories from OI community members. *Gemma's Corner* encourages the OI community to keep sharing with each other, caring for each other, and providing support to one another.



2020 MEMBERS (continued)

Jerry Hall James Hall Steven Hardesty Jim & Kathy Harmer Brian & Kristen Harpish Gerald Harris PhD, PE Tracy Smith Hart John & Jennifer Hartnett Brooke Hershberger Sara Hills **Donald Hoffman** Michelle Hofhine Robert Hogan Eileen Hogan **Douglas Holleman** Ingrid A. Holm, MD Jason & Emily Holub Helen Holubnyczyj Jeanette Hosseini Ruth Hovden Susan Howland Larry & Pat Hufford Faith Hutin Harvey & Judy Irvin Araya Isaacson The Jane M. & Bruce P. Robert Charitable Foundation Jean Jasinski PhD Eamon & Mary Jo Jennings Dennis & Jean Johnson Jennifer Jolivette David & Mary Kahn Barbara Keirns Tara Keppel Kenneth & Karin Keppel Carol Kessler P.J. & Jennifer Kimball Thomas & Sandra King Tina Kingery

2020 MEMBERS (continued)

Daniel Klapperich Josh Klein Carl & Mary Knapp Marie Konopacky Lea-Rachel Kosnik, PhD Gloria Kowbel Paul Kuester Daniel LaBarge Mary Lane Larry & Deborah Lapkin Brian & Kristin Lenahan Elsie Leon Peter & Cheryl Lewis Lawrence Lindvig Joan Lobenberg Michael & Caren Loguercio John & Mandi Lowery Brian J. Mach Fred & Jean Major Betsy & Bob Manela Wallace & Deborah Mangum Cristina Martinez Charlene Maus Betsy Ann McGee **Rita McGrinder** Caroline McLain Dick & Margie McLaughlin Peter & Kathleen McMenamin **Bill McNutt** Mary Merz Martha Ann Messinger Nancy Miller Christina Mills Abdul Mohammed Donna Molony Paula & Tony Moniz Shirley Moody Jane Moore Kathryn Morrison

Fundraising Events

In January and February, the OI Foundation was able to celebrate its 50th anniversary at the *Fine Wines Naples* reception and the 20th annual *Fine Wines Strong Bones Gala DC*. Because of the nationwide shutdowns, in-person fundraising events could not be held for the majority of 2020. But that didn't stop our dedicated group of volunteer event leaders! Events such as the *National Unbreakable Spirit® Walk-n-Wheel*, the *Strong Bones Gala Boston*, and the *Boots and Bling for Better Bones* event in Houston were hosted virtually this year. Fundraising events such as these are critical for funding the programs and resources of the OI Foundation.



1970 Society Members

Thank you to our members who made a very special gift in recognition of the OI Foundation's founding year!

Anthony & Jennifer Benish Ellen Benish Jo Ann Berkenbush John & Nancy Braitmayer Lane & Carol Brundieck William Danner Jeanne Franzone, MD Francis Glorieux, OC, MD, PhD Sherri Goodman Stephanie Greenwood Stephen Gudek, Sr. Famida Hanif-Weddle Gerald Harris, PhD, PE Tracy Smith Hart Priscilla Kilman **Richard Kruse** Ben & Barbara Miller Jonathan & Sharon Mutnick Melanie Rak Robert Sandhaus, MD, PhD Peter Smith, MD Jack & Carol Sprawls S. Jacinta Whyte

2020 MEMBERS (continued)

Pat Morse **Richard & Kathe Morse** Gene & Beth Mulroy Mark Papich & Marcy Murphy Sandra Myers Allen & Kindra Nagle Helen Nahrstedt Joseph & Charlene Nanista Keri Neilson Raymond & Maureen Noeth Joseph & Sharon Nucci Claudia & Sean O'Brien Katherine M. O'Meara Andres Osornio Ocaranza Ann & Borden Painter 🛛 🔍 James Palestrini Frank & Maureen Palestrini Jr. **Tim & Mary Papich** Jeffrey & Angela Paul **Eugene Paykel** Nancy Pesce **Raymond Phillips Audrey Phillips** Judy Picciallo **Dick & Karen Pinney** Henry & Rose Piper Don & Jacquelyn Powell Melinda & Daniel Preston Dennis & Kathi Primus Catherine Ann Pusateri Irene Ratto Roger Gray Renegar Gail Ann Rennetty Donna Rice Edward & Roxanne Rios Conrad & Mary Rivers Kathryn Roberson Guy & Meisie Roberts Benny Robinson

Fundraising Events July 1, 2019 – June 30, 2020

As a small organization for a rare disorder, the OI Foundation relies on volunteer led events held around the country to help raise awareness and funds to support the OI Foundation's mission to improve the lives of people living with osteogenesis imperfecta. Thank you to all the hosts and attendees!

\$100,000 and greater

Boots & Bling for Better Bones Facebook Fundraisers Fine Wines Strong Bones DC

\$50,000 to \$99,999

Fine Wines Reception Naples OI Golf Classic

\$25,000 to \$49,999 Riley's Gathering Place Golf

\$10,000 to \$24,999

Batting For Addison Beef & Brew for Better Bones Bone China Tea

\$5,000 to \$9,999

Miracle Michael Golf National Unbreakable Spirit® Walk-n-Wheel Virtual Power Up Strong Bones Gala Boston

\$2,500 to \$4,999

Alle Shea Project Events Jacaranda Golf Laps for Brittle Bones OI Carnival Potorski Dinner

\$1,000 to \$2,499

Art Auction Blue Jeans for Better Bones OIF Book Club Paint for OI Atkinson Yard Sale

REVENUES FY2020

CONTRIBUTIONS AND GRANTS	\$658,716
EVENT REVENUE	\$504,729
	\$20,086
DIRECT MAIL REVENUE	\$277,258
CONFERENCE REVENUE	\$115,045
	\$71,988
PRODUCT SALES, LESS COST OF GOODS SOLD	(\$3,968)
IN-KIND CONTRIBUTIONS	\$46,719

TOTAL SUPPORT AND REVENUE

\$1,690,573

DISTRIBUTION FY2020

	CLUDING RESEARCH)
PERCENTAGE	64%
AMOUNT	\$1,165,188
FUNDRAISING	
PERCENTAGE	17%
AMOUNT	\$313,927
ADMINISTRATION	
& GENERAL	
PERCENTAGE	19%
AMOUNT	\$344,474
TOTAL EXPENSES	
PERCENTAGE	100%
AMOUNT	\$1,823,589

TOTAL NET ASSETS

\$3,647,178

Sources of Revenue FY 2020



Distribution of Expenses FY 2020



OSTEOGENESIS IMPERFECTA FOUNDATION	

STATEMENT OF FUNCTIONAL EXPENSES Year Ended June 30, 2020

				Prog	Program Services				Suppor	Support Services			
			Education and	q			Public		Management				
	Conferences	10	Support		Research	Av	Awareness	Total	and General	Fundraising	ng	Total	
Salaries and Fringe Benefits	\$ 159,362	22	\$ 290,261	11	141,302	\$	96,533	\$ 687,458	\$ 205,820	\$ 119,573	 	\$ 1,012,851	,851
Bad debt			'				452	452	·				452
Bank Fees	2.0	590	'		67			657	21,307			21,	21,964
Consulting fees			'		21,031		ı	21,031	8,855	·		29,	29,886
Depreciation and amortization	2,189	39	4,079	6,	1,985		1,290	9,543	2,826	1,5	1,576	13,	13,945
Dues and subscriptions	12	24	2,928	8	112		73	3,237	160	(7	236	ŝ	3,633
Equipment Rental and Maintanance	.8	25	1,537	57	748		486	3,596	1,065		594	5	5,255
Event expense	2,063	53	570	0,				2,633	I	140,622	522	143,	143,255
Grants and fellowship			134,308	8	55,500		·	189,808				189,	189,808
Information technology and web support	497	76	12,745	5	983		293	14,518	24,883	0	924	40,	40,325
Insurance	1,024	24	6,086	36	944		650	8,704	1,805	4,8	4,829	15,	15,338
Interest expense			'				,		6,942			6,	6,942
Licenses and permits	11	52	283	33	138		06	663	196		727	1,	1,586
Loss on disposal of assets			'		,				2,000			2,	2,000
Meetings and conferences	34,897	76	1,154	54	36,497		358	72,906	565			73,	73,471
Occupancy	12,122	22	22,287	37	8,113		8,385	50,907	20,734	8,8	8,857	80,	80,498
Office supplies	2,551	51	5,142	12	2,313		1,502	11,508	3,292	5,224	24	20,	20,024
Postage and delivery	407	70	1,758	8	862		240	3,267	532	15,412	12	19,	19,211
Printing and duplicating	5(566	10,834	\$4	514		334	12,248	731	7,5	7,539	20,	20,518
Professional fees	952	52	1,773	73	863		560	4,148	40,514	Q	685	45,	45,347
Survey	1		9,860	09	'			9,860	·			9,	9,860
Telephone	1,512	12	2,817	7	1,371		891	6,591	1,952	1,6	1,679	10,	10,222
Travel	3,280	30	391	11	1,416		633	5,720	137	4,6	4,622	10,	10,479
In-kind expense	122	22	25,228	8	111		20,272	45,733	158	ω	828	46,	46,719
TOTAL EXPENSES	\$ 223,235	22	\$ 534,041	11	274,870	÷	133,042	\$ 1,165,188	\$ 344,474	\$ 313,927	"	\$ 1,823,589	,589

See Notes to Financial Statements.

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2020 MEMBERS (continued)

Simone Rodriguez Andrea Ives & Parke Rublee Archie and Jacinta Ruel Lisa Russo Mitchell & Geraldine Sacks Harvey & Lapaula Sakai Gerald & Sandy Scalzo Judith Schiltz Eric & Kathleen Schlingloff Mary Schlink Wayne & Beverly Schultz Rachelle Grossman & Robert Seelenfreund Julie Selvey Mary Ann Sergio Jessica Sheridan Shriners Hospitals for Children Laura Sices & Peter Garfield Helaine Sikora Nancy Simmers Ila Simpson Gary & Paula Singer Carol Sirkowski Ave-Marie Smith Allan Smith John Soltesz Marc & Allison St. John Katherine Stanhope Marnie Starkey Jeffrey & Sharon Stedman Cindy Steele Nancy Sweeney Dominick Tamburri Claire (Beth) Tatman Rachael Terrin Kyle Thompson Diane M. Tierney Laura Tosi, MD Janet Valdes

2020 United Way/CFC/ Employee Workplace Giving/ Online Charity Giving

Abbvie Employee Engagement Fund Adobe ADP Albertsons Safeway Allstate-The Giving Campaign Amazon Smile America's Charities American Express Company Emp. Giving American Express Foundation Mr. Andrew Anaya Aon Foundation Associated Spring-Hyson Products AT&T United Way/Employee Giving Campaign Automatic Data Processing, Inc Ms. Emily Ballard Bank of America Charitable Foundation, Inc. Bank of America United Way Campaign Bergen County's United Way Best Buy Employee Giving Program Ms. Lori Boatright **Boeing Employee Good** Neighbor Fund **Bright Funds Foundation** Tory Brooks Blaine & Stacy Buxton Ms. Stephanie Carlos The CarMax Foundation Chevron Workplace Giving Robert & Mary Clodfelter

Community Health Charities Mr. Jimmie Cox Mr. Katherine Dektar Duke Energy Ms. Donna Edler Elsevier Science-Book Royalty **Evolve Fieldwork Exelon** Corporation Mr. Kevin Frisch Frontstream Gartner Michael & Carol Goebel Ms. Stephanie Goode Google Greater Horizons-Charity Giving Card Fund Harvest Ms. Emily Heller Mr. Kevin Hench Intuit Foundation Intuitive Foundation Ms. Joanne Jackson Yoyxuan Jin Ms. Ashley Johnson Johnson & Johnson Family of Companies JPMorgan Chase Foundation-Matching Gift Mr. Joel Keith Kimberly-Clark Foundation Ms. Carol Kirchhoff **KLA** Foundation Ms. Brenda Kosovan Mr. Mark Lee Liberty Mutual Group, Inc.

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