

2020 ANNUAL REPORT



Living Well with an Unbreakable Spirit®

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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 you!



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 OI; 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.





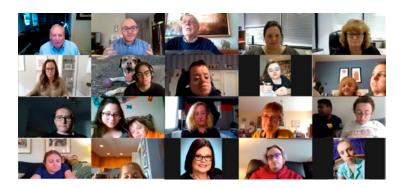
COVID-19 Response

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 DeBlieck

Julia Delgado

Donna Derby

John & Lori DeRosa

Gail Desmarais

Ken & Diane Dietterich

2020 MEMBERS (continued)

Sean & Jamie DiGeorge

Peg 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

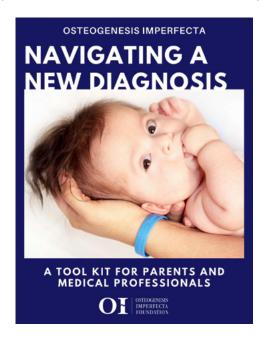
Anat Haimovici

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.



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.







(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

(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

CONTRIBUTIONS

AND GRANTS \$658,716

EVENT REVENUE \$504,729

INVESTMENT INCOME \$20,086

DIRECT MAIL REVENUE \$277,258

CONFERENCE REVENUE \$115,045

CONTRACT REVENUE \$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

PROGRAM SERVICES (INCLUDING RESEARCH)

PERCENTAGE AMOUNT \$1,165,188

FUNDRAISING

PERCENTAGE 17% AMOUNT \$313,927

ADMINISTRATION

& GENERAL

PERCENTAGE 19% **AMOUNT** \$344,474

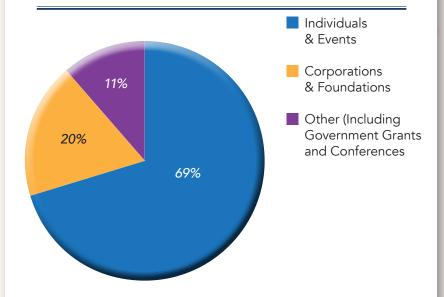
TOTAL EXPENSES

PERCENTAGE 100% **AMOUNT** \$1,823,589

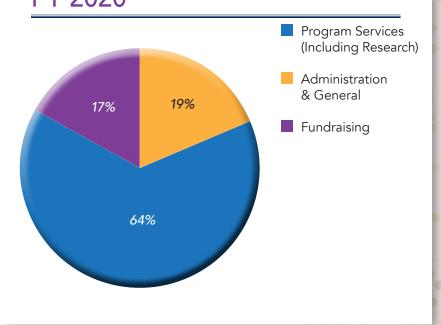
TOTAL NET ASSETS

\$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

				Pı	rogram	Program Services				Support	Support Services			
			Edt	Education and			Pl	Public		Management				
	Co	nferences		Support	Res	Research	Awa	Awareness	Total	and General	Fundraising		Total	
Salaries and Fringe Benefits	↔	\$ 159,362	↔	290,261	↔	141,302	↔	96,533	\$ 687,458	\$ 205,820	\$ 119,573	↔	1,012,851	
Bad debt		1				1		452	452				452	
Bank Fees		290		1		29		ı	657	21,307	ı		21,964	
Consulting fees				,		21,031		1	21,031	8,855	•		29,886	
Depreciation and amortization		2,189		4,079		1,985		1,290	9,543	2,826	1,576		13,945	
Dues and subscriptions		124		2,928		112		73	3,237	160	236		3,633	
Equipment Rental and Maintanance		825		1,537		748		486	3,596	1,065	594		5,255	
Event expense		2,063		570				1	2,633	1	140,622		143,255	
Grants and fellowship		1		134,308		55,500		1	189,808				189,808	
Information technology and web support		497		12,745		983		293	14,518	24,883	924		40,325	
Insurance		1,024		980'9		944		650	8,704	1,805	4,829		15,338	
Interest expense								1		6,942	•		6,942	
Licenses and permits		152		283		138		06	663	196	727		1,586	
Loss on disposal of assets								1		2,000	•		2,000	
Meetings and conferences		34,897		1,154		36,497		358	72,906	265	1		73,471	
Occupancy		12,122		22,287		8,113		8,385	50,907	20,734	8,857		80,498	
Office supplies		2,551		5,142		2,313		1,502	11,508	3,292	5,224		20,024	
Postage and delivery		407		1,758		862		240	3,267	532	15,412		19,211	
Printing and duplicating		266		10,834		514		334	12,248	731	7,539		20,518	
Professional fees		952		1,773		863		260	4,148	40,514	685		45,347	
Survey		1		098'6		1		1	098'6				098'6	
Telephone		1,512		2,817		1,371		891	6,591	1,952	1,679		10,222	
Travel		3,280		391		1,416		633	5,720	137	4,622		10,479	
In-kind expense		122		25,228		111		20,272	45,733	158	828		46,719	
TOTAL EXPENSES	↔	223,235	₩.	534,041	↔	274,870	₩.	133,042	\$ 1,165,188	\$ 344,474	\$ 313,927	↔	1,823,589	
										1				

See Notes to Financial Statements.

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Adobe

ADP

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