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Recurrent Pregnancy Loss Association
Impact Report 2022



LETTER FROM THE PRESIDENT

Dear Friends,

RPLA had several accomplishments in 2022 - I could not be more grateful for or proud of our Board and our community of supporters.

Most notably, in 2022 we launched the **RPL Community Registry** and awarded our first **RPLA-ASRM Recurrent Pregnancy Loss Research Grant.** We have been working towards these two milestones since our inception in 2019. We knew from the start that a core pillar of our mission was to enable research, and we are confident in our conviction that when families work in partnership with scientists and healthcare providers, progress can be accelerated.

The RPL Research Grant is funded entirely by individual contributors, many if not most of whom have been impacted by pregnancy loss. Participation in the RPL Community Registry is entirely voluntary. That both of these programs have been established within years of our launch is, to me, a powerful indicator of how hungry our community is for answers, and how desperately we want to prevent future, unnecessary losses.



2022 also saw a "changing of the guard." Three of our founding Directors completed their term and have rolled off the Board. I will be forever thankful for Serena Hohmann, who was my strategic thought partner; Katherine Konefal, who taught me the ins and outs of fundraising, and; Melanie Thomas, who was instrumental in starting our monthly **RPL Support Group**.

In addition, I am thankful and pleased to introduce four new Directors: Ann Coyle, a fetal-care and perinatal bereavement nurse; Joseph Konefal, vice president of research and development for XOS, a Danaher company; Melissa Loonan, Esq. who works in regulatory services for US Bank, and; Ashlee Van Schyndel, a PhD candidate in public health at the University of Illinois Chicago.

They, along with my other talented volunteer Directors, have set big goals for 2023. Notably, we plan to expand and develop our Advocacy Initiatives, form partnerships to leverage the RPL Community Registry data, and write a white paper on the lived experience of RPL, establish a multidisciplinary network of providers interested in pregnancy loss. Thank you for your continued interest in and support of our work.

Sincerely, Megan Hanson, President



OUR YEAR IN NUMBERS



\$64,347 Raised 186

Donors



Granted for RPL Research



Support Group Sessions



"Ask the Expert" **Conversations**



Members of the RPL Community Registry



Followers on Social Media



Flowers in our **Virtual Memorial** Garden



ORGANIZATIONAL OVERVIEW

missior

RPLA is dedicated to:

- Eliminating recurrent pregnancy loss through the advancement of research into causes and treatments;
- Providing support and resources to those affected; and
- Increasing awareness of the impact of miscarriage and fertility challenges on individuals and families.

orograms

Community Initiatives: Providing support and resources to help people navigate RPL and their family building process

Advocacy Initiatives: Increasing awareness about the impact of multiple miscarriages and why additional attention and research are necessary

Scientific Initiatives: Supporting activities that advance our understanding of RPL and how to manage it

eople

2022 Board of Directors

Megan Hanson (President), Volunteer Serena Hohmann (Vice President), Astellas Pharma

Benjamin Burnham (Treasurer), Amazon Katherine Konefal (Secretary), Volunteer Mari Trevino Glass, Trevino Consulting Group

Ronald Librizzi, DO, Retired, Virtua Health Amy Henderson Riley, DrPH, Thomas Jefferson University Jessica Ryniec, MD, CCRM Fertility Boston Melanie Thomas, MSW, CHI Franciscan Health

Incoming Directors

Ann Coyle, RNC, Virtua Health Joseph Konefal, XOS Melissa Loonan, Esq, US Bank Ashlee VanSchyndel, MPH, University of Illinois Chicago

Scientific Advisors

Winifred Mak, MD, PhD, Dell Medical School, University of Texas at Austin Dana McQueen, MD, MAS, RMA Northern California Hannah Palac, MS, AbbVie Elizabeth Sefton, PhD, Stanford University



PROGRAM HIGHLIGHTS



Co-Founders Ben and Megan with Dr. Workalemahu at the ASRM Congress

The First RPLA-ASRM RPL Research **Grant was Awarded**

We were thrilled to award our first \$40,000 research grant to Dr. Tsegaselassi Workalemahu, PhD, MSc, at the University of Utah.

Dr. Workalemahu is an Assistant Professor of obstetrics and gynecology in the division of maternal-fetal medicine and an adjunct Assistant Professor of internal medicine in the division of epidemiology.

His project, titled "Inherited Genetic Variants and Unexplained RPL," will conduct whole genome sequencing analyses of DNA from families who have lost pregnancies with the aim of determining specific genetic mutations that cause pregnancy loss. These types of discoveries could help make diagnostic evaluations and interventions for RPL more specific.

The "RPL Community Registry" **Launched in March**

The RPL Community Registry is a database that contains information about patients and their medical history. The registry will help doctors and scientists answer questions, inform course of treatment, and generate new research hypotheses to test. It can also be used to help connect patients to clinical trials and other research opportunities that may be relevant to their individual circumstances.

The formation of a patient registry is the first step toward performing meaningful research on recurrent pregnancy loss.

- Dr. Dana McQueen, RMA

Here is a data snapshot* as of January 2023:

- 301 people registered and fully consented
- 815 reported pregnancy losses
- 84% have been pregnant more than 3 times
 41% have living children (by some means)
- 88% started trying to conceive before age 35 (48% before age 30)

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PROGRAM HIGHLIGHTS

Expert Providers Answered Community Questions

We continue to hold virtual, live events where RPL community members can directly ask questions to expert doctors or other professionals. These "Ask the Expert" sessions are then shared and saved on our website and social media pages.

In 2022, we sat down with five incredible experts:

Genetics of Pregnancy Loss



Dr. Ruth Lathi

Professor of obstetrics and gynecology and Director of the RPL program at Stanford University



Dr. Christy Tise

Assistant Professor in the division of medical genetics at Stanford University

Genetic Testing for Recurrent Miscarriage



Katie Lee Hornberger
Certified Genetic Counselor

Myths and Facts about Diet and Miscarriage



Susan Portz
Registered Dietician and Coach

Blood Clotting and Pregnancy Loss



Dr. Gregory Piazza

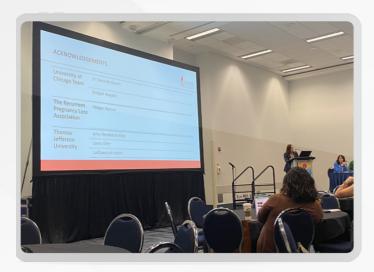
Associate Professor at Harvard Medical School and faculty in the cardiovascular division of Brigham & Women's Hospital

Our Virtual Memorial Garden Flourished

Often loss parents, particularly those who experienced early pregnancy loss, struggle to find ways to memorialize their babies. That's why RPLA created our **Virtual Memorial Garden**. Planting a flower in our garden is free and unlimited. It's a small way that we can remember our losses and hold space for our shared grief. Currently, 168 flowers are eternally in bloom in our garden.



PROGRAM HIGHLIGHTS



We Are Helping Improve Care for RPL Families

RPLA partnered with the University of Chicago on a research project to understand the lived experience of recurrent pregnancy loss.

The research project involved conducting in-depth interviews with 30 members of the RPL Community.

Themes were identified and used to determine ways that care practices could be improved for loss parents.

Initial findings were presented during a symposium at the 2022 ASRM (American Society for Reproductive Medicine) Congress (pictured above). Findings were also used to inform a post-graduate training on trauma-informed care at the Congress.

We Provide A Safe Space for Support and Validation

The experience of RPL can feel isolating and we don't want anyone to feel alone in their struggle. That's why we continue to host our monthly, free, virtual support group.

Sometimes, the support group is the first interaction people have with others who've experienced multiple losses. Said one attendee, "The first time I came, it blew me away. It was like having my mind read."

By continuing to hold this space, we hope to change the narrative of RPL from one of lonesomeness and pain to one of togetherness and mutual strength.





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FINANCIAL PERFORMANCE

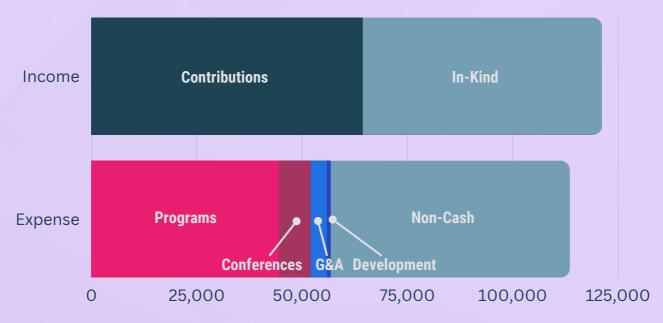
In 2022 RPLA received \$64,347 in unrestricted gifts from 186 donors. This represents a 8% decrease in contributions from FY2021.

Other income included in-kind Executive Director (ED) services valued at \$56,766 for the year. Total income was \$121,161.

Cash expenses for the year were \$56,688. The largest single expense was \$40,000 granted to Dr. Workalemahu at the University of Utah. Management and general expenses totaled \$3,772, representing 5.8% of contributions. Fundraising and development expenses were \$1,008, representing 1.5% of contributions.

Net gain for the year was \$7,708. Cash balance as of December 31, 2022 was \$106,809. Ending FY2022 in a strong cash position was an operational necessity to disburse the 2023 RPLA-ASRM Research Award in April 2023.

No money was spent on salaries. RPLA is entirely volunteer run. Executive Director services were recognized as an in-kind contribution along with an offsetting non-cash expense to represent the work that is currently done by our Board president on a volunteer basis and our intent to eventually hire a full-time, paid ED.





FINANCIAL STATEMENTS

Statement of Financial Position

| Assets | Fiscal Year Ended December 31, 2022 |
|----------------------------|--|
| Checking | \$96,246 |
| Cash in Transit | \$7,695 |
| Accounts Receivable | \$2,868 |
| | Total Assets \$106,809 |
| Liabilities | |
| | Total Liabilities \$0 |
| Net Assets | |
| General Fund - Unresticted | \$106,809 |
| | Total Net Assets \$106,809 |
| | Total Liabilities + Net Assets \$106,809 |

Statement of Comprehensive Income

| Interest Earned In-Kind Donations Total Income \$1 | \$64,347 \$21 \$56,766 |
|--|------------------------------|
| In-Kind Donations Total Income \$7 Expenses Programs | |
| Expenses Programs | \$56,766 |
| Expenses Programs | |
| Programs | 21,162 |
| · · | |
| Fundraising & Development | \$44,393 |
| i unulaising & Development | \$1,008 |
| General & Administrative | \$3,772 |
| Conference Attendance | \$7,513 |
| Executive Director Services (non-cash) | \$56,766 |
| Total Expenses \$1 | 13,453 |
| Net Income (Loss) | |



ACKNOWLEDGEMENTS

\$10,000 and Up

· Rev. Jeanne Hanson

\$5,000 to \$9,999

- Dr. Joseph & Mrs. Karen Konefal
- Ben Burnham & Megan Hanson

\$1,000 to \$4,999

- · Randy & Nancy Green
- Judy Jones
- · Mike & Laurie Burnham
- Google
- · Paul Sohn
- · Carol Lavin Bernick
- · Sonja Koenig
- · Gail Palac
- . Bob & Jane Simpson
- · Brandon & Amy Riley
- Joey & Kate Konefal
- · Richard & Michelle Anderson
- Serena Hohmann
- Beth Rahn
- Dr. Ronald & Mrs. Robin Librizzi
- . Clint & Melanie Thomas
- CCRM Boston

\$500 to \$999

- Drs. Jake Gillen & Natalie Karp
- Pete Greenberg & Carrie Harwood

\$100 to \$499

- Blackbaud Giving Fund
- · Craig & Nancy Davis
- Chan Zuckerberg Foundation
- Dr. Gary & Mrs. Michelle Polvere
- · Abhi & Jasmi Shah
- · Capital Group
- · Orion & Jacqueline Hindawi
- Dr. Rev. Zina Jacque
- · Robert Lloyd Corkin Foundation
- KC Sylvestre

\$100 to \$499 cont.

- · Kimberly O'Loughlin
- Maureen Shanahan
- Adam & Christy Wolf
- Michelle Valiukenas
- · Eric & Amberly Zwiener
- Microsoft
- · Dr. Jessica & Mr. John Ryniec
- John Rula & Chenault Taylor
- Twilo
- Helen Wang
- · Pascal & Allie Arcese
- Hannah Asmar
- Rima Binder
- Chris & Katie Bolling
- · Dr. Michela Blain & Mr. Scott Peppel
- Kendra Brewer
- Krista Carboni
- · Jim & Melissa Coleman
- Kathleen DuRoss
- Mary Evdjukian
- Ginnie Greene
- Jacquelyn Harvey
- Alan Hougum
- Dr. Brent & Mrs. Susan Kaziny
- Tom & Melissa Loonan
- Dr. Dana McQueen
- Chris & Claudia Murray
- Jennifer Pennington
- · Abbe Pick
- · Christine Rhode
- · Allison Schaaf
- Casey Shpreyregin
- Starbucks
- · Jim & Alissa Staples
- Laryssa Storozuk
- Debbie Talbot
- · Doug Twait
- Matt & Ayn Williams

\$50 to \$99

- Ted & Andrea Eigel
- Dave & Kanako Lake
- Andrea Marasso
- Peggy Henderson
- Elana Greensberg
- Nick & Julia Borst
- Brad Brink
- Vigdis Bronder & Brian Haas
- Kody Burson
- · Denise Caccavari
- Lourdes Catala
- Benna Curran
- Daniella DeArtista
- Carly Dummer & Danny Room
- Forrest Hanson
- Robert Henderson
- · Kara Johansen
- · Deedie Jones
- Jazzie Juris-Ampig
- Mani Kavuru
- Linda Kondikoff
- Emily Kucik
- Scott Mandel
- Jason Matkowsky
- Amber Matz
- Davis McCall
- Elizabeth McMorrow
- Jessica Merizan
- Jody Morton
- Network for Good
- Pam O'Brien
- Hannah Palac
- Pooja Shevade
- Lisa Page Tuten
- Erin Vicini
- Jennie Wike
- Xueson You



ACKNOWLEDGEMENTS

Up to \$49

- · Annika Rodriguez
- Ann Marie Vazquez
- Justin Viskoc
- Jesse Sandoz
- Daniel Schneider
- · Gabby Clark
- · Tricia Aspinwall
- · Stephany Burns
- · Stacie Dyer
- Theresa Fitzpatrick-Barkley
- Tom & Nancy Burnham
- · Lori Frederick
- · Ryan Frederick
- · Kim Gates
- · Sidney Gisberg
- · Harvey Hinman
- Rolandria Justice-Emenuga
- · Sandra Kelly
- Melissa Wallace Lemaster
- Katrina Lepinski
- · Melinda Matula
- Daniel McLaughlin
- · Kelsey Pigneri

- Jessica Rohde
- Danielle Vellucci
- · Liz Mackie Venturato
- Maggie Wilson
- ZS Associates
- Gabriella Geatti
- · Katie B
- Ronda Oberender Becker
- Kimberly Chalek
- Rebecca Chavez
- Martyna Feather
- · Lauren Gould
- Ali Guerriero
- Celia Hipsman
- · Michelle Hoon
- Infertility Coach Kiki
- Janani Kumaragurubaran
- Jennifer LaPaca
- Lisa Masciarelli
- · Kelly Park
- Annu Priya
- Carrie Sarlo Randazzo
- Tracy Rose
- Katie Mangan Siegel

- April Vandepas
- Ruth Wilson
- Dave & Abi Montgomery
- Stephanie Turcotte
- · Kim Garbedian
- · Kate Weldon LeBlanc
- Matt Galusha
- · Rita Pihra-Majurinen
- Xanthippe Maverick
- Mary Allen
- Kristin Lebon
- Jane Masters
- Amanda Nied
- · Anna Smith
- Voya Financial
- · Allison Ward
- · Maggie Shaw Zmijewski
- Julie Cannon
- Christina Cummings
- · Benjamin Hickson
- Thea O'Grady
- What's Up Dog

We thank you for your continued support of our mission.

Contact

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RPLA is a 501(c)(3) non-profit organization. EIN 84-3993828

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