Welcome!
From Kathryn Stephens, IDF Interim CEO,

I would like to wish you a warm welcome to the Immune Deficiency Foundation 2021 Primary Immunodeficiency Conference!

Over the last few months, I've had the great pleasure of being welcomed into the primary immunodeficiency (PI) community. I've been able to see what it's like for this zebra strong rare disease community and know the impact that this conference has on all those who are living with PI. The last year hasn't been easy for anyone, and now more than ever, this opportunity to connect—even virtually—is something that we all can benefit from.

Over the next few days, you will hear from physicians, nurses, healthcare professionals, industry experts, and others living with PI who understand the unique nature of these rare, chronic disorders. You will have the chance to talk with others who have similar stories as you. Most importantly, your time here will help you and your loved ones better understand PI and help improve your overall quality of life.

During this time, I hope that you take everything you're learning and use it to further advance awareness of our community. Share images and stories on social media (and tag IDF). By doing so, you could help someone else find their home here within the IDF community and make a difference in the lives of others.

I hope you enjoy your time here this week, learn something new, and feel empowered by our community.

The primary immunodeficiency (PI) community often identifies with zebras. This is based on an old saying. In medical school, many doctors learn the saying, “when you hear hoof beats, think horses, not zebras” and are taught to focus on the likeliest possibilities when making a diagnosis, not the unusual ones. However, sometimes physicians need to look for a zebra. People with PI are the zebras of the medical world. So IDF says THINK ZEBRA!

People with PI, along with their family and friends, can be seen wearing zebra striped clothes and using accessories adorned with black and white stripes. All ages identify with zebras, and it has been an especially good way for children with PI to describe their disease to others—they are like zebras.
Interactive Platform
While you won’t be there in person, you just might feel like you are with the virtual environment and video chat functionality. More than 30 exhibitors will be there to discuss lifestyle management, recent scientific research, and treatment options for primary immunodeficiency. All meeting rooms and lounges can be reached through the lobby with intuitive navigation and live support.

Youth Programming
The first day of the conference (Wednesday, June 23) is reserved for our youngest zebras. Special sessions are designed for children, tweens, teens, and young adults. In addition to educational sessions, there will be an interactive art project, a virtual escape room, and a “cocktail” hour for young adults.

Programación En Español
Uno de los aspectos más destacados de la Conferencia de PI será el lanzamiento de “Conectarse al Grupo: Grupo de Apoyo para Pacientes y Familiares”, ¡nuestro primer Grupo de apoyo para caciones y familiares realizado en español! 11 sesiones contarán con subtítulos en español, lo que ofrecerá un ambiente inclusivo y acogedor para todos los participantes. Estas sesiones incluyen dos sesiones de grupos de apoyo para padres, los tres paneles de discusión y sesiones educativas sobre COVID-19, terapia de Ig, CVID, inmunizaciones, la conexión entre COVID / asma y derechos laborales.

Engaging Panel Discussion & Educational Sessions
Because the event is virtual, travel is no issue for our presenters! Joining the PI Conference are world-class immunologists and life management experts who will provide sessions on a range of topics related to primary immunodeficiency. In addition, each day, we will be hosting panel discussions on topics that address issues that range far beyond just PI.

Special Events & Celebrations
On Thursday (June 24) evening, there will be a VIP & Awards reception streamed live to Facebook that you don’t want to miss. Awards include the IDF Scientific Achievement Award, the Art of Nursing Award, the Plasma Hero Award, and the Community Hero Award. On Friday (June 25) evening, you’ll want to participate in Joshua Seth and his live online mind-reading experience: Virtually Connected. His shows are unique, interactive, and engaging for all audiences.

Connections
Opportunities for connection abound at the IDF Primary Immunodeficiency Conference. Peer connections will happen each day where you can join based on age, family dynamic, or diagnosis. There is even a connections group for our international attendees!

And if you’re craving one-on-one interaction, you can reach out to exhibitors and other attendees for questions or conversations in between sessions. You can even get a bit competitive while exploring the platform, trying to earn points on the leaderboard!

Clinician Education
Thanks to the expertise and partnership of Clinical Immunology Society (CIS), this event is not just limited to patients and families. Wednesday through Friday, there will be clinician education opportunities with continuing education credits provided by partner organizations.
Create an IDF My Account

Use or create an IDF My Account to make sure your information is up-to-date, including your email address, mailing address, diagnosis information, and more. These pieces of information allow us to connect with you and give you relevant information from IDF.

Join the IDF community and optimize your experience on the IDF website. www.primaryimmune.org/myaccount.

Connect & Share with the PI Community

Connect and share with others during the 2021 Primary Immunodeficiency Conference and all year round by following us on our social networks. See what we’re posting, get live updates of conference happenings, and use hashtags to see what others are sharing! Don’t forget to post and share your experiences, too!

IDF 2021 Primary Immunodeficiency Conference Hashtags

#IDF2021PIConference #primaryimmunodeficiency #primaryimmune
#ThinkZebra #livingwithPI #zebrastrong

Where to Find Us

IDF Facebook
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www.youtube.com/IDFvideos
Hosting a DIY Fundraiser allows you to have your own personalized fundraising page that includes all the details of your unique event. Once you create your page, you can share it with your network so that your friends, family, and community can learn more about participation. They can make donations to support you and IDF right on your customized web page.

When it comes to DIY fundraising, the sky is the limit. No matter how big or small your fundraiser, you're making a difference, and individuals with primary immunodeficiencies (PI) across the country will benefit from your efforts.

Learn how you can get involved at www.primaryimmune.org/diy-fundraising
Thank You to Our IDF 2021 Primary Immunodeficiency Conference Sponsors!

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**Exhibitors**
Exhibitors: Accredo, BPL, Enzyvant, Kedrion, Koru, Pharming, Soleo, X4, Black in Immuno, CGD Association of America, Clinical Immunological Society (CIS), Genetic Disorders of Mucociliary Clearance Consortium (GDMCC), Hyper IgM Foundation, Immunoglobulin National Society (IgNS), Plasma Protein Therapeutics Association (PPTA), Primary Ciliary Dyskinesia (PCD), Primary Immune Deficiency Treatment Consortium (PIDTC), Wiskott-Aldrich Foundation
Real stories from real people with PI

Visit our booth to meet people with PI and hear about their experiences with Hizentra therapy, prefilled syringes, and their PI treatment journey.

The information presented here is intended for US audiences. Prescribing information may vary, depending on local approval in each country. Therefore, before prescribing this product, always refer to local materials, such as the prescribing information, product monograph, and/or the summary of product characteristics in your country. Visit CSLBehring.com for more information about CSL Behring.

Immediately report to your physician any of the following symptoms, which could be signs of serious adverse reactions to Hizentra:

- Reduced urination, sudden weight gain, or swelling in your legs (possible signs of a kidney problem).
- Pain and/or swelling or discoloration of an arm or leg, unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, or numbness/weakness on one side of the body (possible signs of a blood clot).
- Bad headache with nausea; vomiting; stiff neck; fever; and sensitivity to light (possible signs of meningitis).
- Brown or red urine; rapid heart rate; yellowing of the skin or eyes; chest pains or breathing trouble; fever over 100°F (possible symptoms of other conditions that require prompt treatment).

Hizentra is made from human blood. The risk of transmission of infectious agents, including viruses and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent and its variant (vCJD), cannot be completely eliminated.

The most common side effects in the clinical trials for Hizentra include redness, swelling, itching, and/or bruising at the infusion site; headache; chest, joint or back pain; diarrhea; tiredness; cough; rash; itching; fever, nausea, and vomiting. These are not the only side effects possible. Tell your doctor about any side effect that bothers you or does not go away.

Before receiving any vaccine, tell immunizing physician if you have had recent therapy with Hizentra, as effectiveness of the vaccine could be compromised.

Please see full prescribing information for Hizentra, including boxed warning and the patient product information.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

You can also report side effects to CSL Behring’s Pharmacovigilance Department at 1-866-915-6958.

Biotherapies for Life® CSL Behring
Meet the latest innovation in Ig

Simplify infusions with the convenience of Hizentra prefilled syringes

- No more vial transfers! Prefilled syringes may reduce steps and effort during infusion preparation vs. vials, depending on dose.
- Hizentra prefilled syringes are transferred to a pump syringe using a syringe-to-syringe transfer device.

Ask for the first and only prefilled syringes for Ig to further personalize therapy today.

Visit HizentraPFS.com to learn more.

*lg=immunoglobulin

Important Safety Information

Hizentra®, Immune Globulin Subcutaneous (Human), 20% Liquid, is a prescription medicine used to treat:
- Primary immune deficiency (PI) in patients 2 years and older
- Chronic inflammatory demyelinating polyneuropathy (CIDP) in adults

WARNING: Thrombosis (blood clots) can occur with immune globulin products, including Hizentra. Risk factors can include: advanced age, prolonged immobilization, a history of blood clotting or hyperviscosity (blood thickness), use of estrogens, installed vascular catheters, and cardiovascular risk factors.

If you are at high risk of blood clots, your doctor will prescribe Hizentra at the minimum dose and infusion rate practicable and will monitor for signs of clotting events and hyperviscosity. Always drink sufficient fluids before infusing Hizentra.

See your doctor for a full explanation, and the full prescribing information for complete boxed warning.

Treatment with Hizentra might not be possible if your doctor determines you have hyperprolinemia (too much proline in the blood), or are IgA-deficient with antibodies to IgA and a history of hypersensitivity. Tell your doctor if you have previously had a severe allergic reaction (including anaphylaxis) to the administration of human immune globulin. Tell your doctor right away or go to the emergency room if you have hives, trouble breathing, wheezing, dizziness, or fainting. These could be signs of a bad allergic reaction.

Inform your doctor of any medications you are taking, as well as any medical conditions you may have had, especially if you have a history of diseases related to the heart or blood vessels, or have been immobile for some time. Inform your physician if you are pregnant or nursing, or plan to become pregnant.

Infuse Hizentra under your skin only; do not inject into a blood vessel. Self-administer Hizentra only after having been taught to do so by your doctor or other healthcare professional, and having received dosing instructions for treating your condition.
Grifols is a global healthcare company with more than 100 years of history in improving the health and well-being of people around the world.

We produce medicines for you and provide your healthcare professionals with tools, information, and services to help them deliver expert medical care to combat rare, chronic, and sometimes life-threatening conditions.
IDF Friends is a private, supportive online community created by the Immune Deficiency Foundation (IDF) and designed for everyone in the PI Community, including you! As a part of IDF Friends, you can share stories, discuss symptoms, get advice, and connect with others from across the country in similar situations. After you leave the IDF 2021 Primary Immunodeficiency Conference, visit IDF Friends to share experiences from the various sessions and events taking place! We want you to take part and keep the conversation going. Join us at www.idffriends.org.

Stay in Touch with IDF FRIENdS

BPL is committed to providing a continuous and reliable supply of high-quality, plasma-based products to the patients, healthcare professionals, and customers we serve. Please visit us at www.bpl-us.com.

The SCID Compass program offers support for families as they navigate the journey of caring for their infants diagnosed with severe combined immunodeficiency, or SCID, a rare genetic disorder. www.scidcompass.org
IS PROUD TO SUPPORT THE
Immune Deficiency Foundation
at the 2021 National Conference

Octapharma has been committed to patient care and medical innovation since 1983. Our core focus is the development and production of human plasma proteins from human plasma and human cell lines. Octapharma employs more than 9,000 people worldwide to support the treatment of patients in 118 countries with coagulation disorders, immune disorders, and other critical illnesses.

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Please visit us at www.bpl-us.com

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for the Primary Immunodeficiencies
Every hero starts somewhere.

Donate plasma. www.plasmahero.org

Stop by the IDF BOOTHs

Get the chance to talk to IDF staff about various programs and services that could benefit you, at the IDF booths in the virtual Exhibit Hall!

IDF Walk for PI & Fundraising
Stride with IDF pride and learn all the ways you can help support IDF through fundraising!

IDF Volunteer Opportunities
Learn how you can use your talents in a volunteer position with IDF!

SCID Compass
Wherever you are on your journey with SCID, you can find support!

IDF Advocacy
Find out how you can use your voice to advocate for the PI community!

Plasma Hero
Now more than ever we need heroes to donate plasma and raise awareness!

Share Your Story
Share your story with the PI community and inspire others like you!
The IDF 2021 Primary Immunodeficiency Conference is packed with sessions and activities that we hope you enjoy. To get the most out of the conference, we encourage you to pace yourself as you follow your schedule and use the virtual platform to its full capabilities. All times noted are ET.

**WEDNESDAY, JUNE 23**

### Youth & Young Adult Program

12:00-12:45 PM  
**Stand Up for PI**  
(Youth & Teens - up to 18 years)

12:45-1:15 PM  
**What is PI?**  
(Youth & Tweens, 5-12 years)

2:00-2:30 PM  
**Interactive Art Project**  
(Youth & Tweens, 5-12 years)

2:45-3:15 PM  
**Life with PI: School**  
(Tweens, Teens, & YA, 12-20 years)

3:30-4:00 PM  
**Get Creative with DIY**  
(Up to 18 years)

4:00-4:45 PM  
**Parent Session: The Elementary Years**

6:00-7:00 PM  
**Parent Session: Off to High School & College**

### 6:00-7:00 PM  
**Young Adult Social Hour**  
(21-35 years)

7:00-8:30 PM  
**Virtual Escape Room**  
(Teens & YA, 13-20 years)

### Peer Connections

5:00-6:00 PM  
**The Support Team: Breakout Zoom**  
Meetings for:  
Spouses, Partners, & Friends  
Parents of Young Adults (18+)  
Parents of Children & Teens (up to 17)

6:00-7:00 PM  
**Adults with PI: Breakout Zoom**  
Meetings for:  
Adults 36-49  
Adults 50+  
Hispanic/Latino Community (Grupo de Apoyo de Pares)

*Presented or captioned in Spanish*
THURSDAY, JUNE 24

11:00-11:45 AM
IDF Welcome & General Session*
John Seymour, IDF Board of Trustees Chair
Tracy Shaw, IDF Board of Trustees

12:00-12:45 PM
Primary Immunodeficiency 101*
Megan Cooper, MD, PhD
Gain a greater understanding of immune system function and what part of your immune system is affected based on your PI diagnosis.

Genetic Screening & PI: Understanding the Whole Exome & Whole Genome
Manish Butte, MD, PhD
Learn about these two methods of DNA sequencing used to test for genetic disorders by relying on new technologies that allow rapid sequencing of large amounts of DNA.

1:00-2:00 PM
Panel Discussion: The Public Face of PI*

2:15-3:45 PM
Diagnosis Specific Peer Connections:
Breakout Meetings for:
- X-linked Agammaglobulinemia (XLA)
- Common Variable Immune Deficiency (CVID)
- Specific Antibody Deficiency, IgG Subclass Deficiency, & Hypogammaglobulinemia
- Combined Immune Deficiency
- Selective IgA & IgM Deficiencies

3:30-4:30 PM
Diagnosis Specific Peer Connections:
Breakout Meetings for:
- APS Type 1 & APECED
- Chronic Granulomatous Disease (CGD)
- Hyper IgM
- Severe Combined Immunodeficiency (SCID)
- Wiskott-Aldrich Syndrome (WAS)
- Ultra-Rare Diagnoses

2:15-3:45 PM
SCID Compass Program
Alissa Creamer, IDF Staff
Emma Mertens, IDF Staff
Fri Mofor, IDF Staff

4:45-5:45 PM
Rare of the Rare Snapshot Session

6:30-7:30 PM
VIP Reception & Award Ceremony
FRIDAY, JUNE 25

10:00-10:30 AM
Coffee Chat: Good Morning with IDF

10:45-11:45 AM
COVID-19: Immunity within Reach*
Kathleen Sullivan, MD, PhD

This session will cover what we have learned about COVID-19, the treatment and outcome of individuals diagnosed with primary immunodeficiency who were infected with the virus, an update about current vaccines, and expectations in regards to reaching immunity by the end of the year.

12:00-12:45 PM
Ig Therapy: Your Questions Answered
Linda Anastasia, BSN,RN, CPN, IgCN
Carla Duff, CPNP, MSN, CCRP, IgCN
M. Elizabeth Younger, CPNP, PhD

Ig therapy plays a significant role in the lives of many people with PI. Basic information about this important therapy will be presented. Then, participants will join a nurse in a breakout room who will answer their questions.

12:00-12:45 PM (continued)
Antibiotics: Treatment for Chronic & Acute Infection
Monica G. Lawrence, MD

Gain a greater understanding of how antibiotics are prescribed for chronic and acute infections. Get your questions about antibiotic resistance and prophylactic antibiotics answered.

1:00-2:00 PM
Panel Discussion: Health Equity*

2:15-2:30 PM
Managing Your CVID*
Paul Maglione, MD, PhD

Diagnosis Specific Peer Connections:
Breakout Meetings for:
- X-linked Agammaglobulinemia (XLA)
- Specific Antibody Deficiency, IgG Subclass Deficiency, & Hypogammaglobulinemia
- IgA & IgM Deficiencies
- Combined Immune Deficiency
- APS Type 1 & APECED
- CGD
- SCID
- WAS
- Hyper IgM Syndrome (HIGM)

*Presented or captioned in Spanish
FRIDAY, JUNE 25

3:45-4:30 PM
Managing Chronic Sinusitis
Marc Riedl, MD, MS
Chronic sinusitis is a common medical condition affecting over 10% of the general population. In the PI community it is a very complication due to the increased risk of infection and inflammation. Attend this session to learn about contributing factors, evaluation, and treatment.

Immunizations in the PI Community*
Howard Lederman, MD, PhD
M. Elizabeth Younger, CRNP, PhD
With over 400 types of PI that differ so vastly in terms of what part of the immune system is not working properly there are many questions about when a specific vaccine should be administered or withheld. This session will provide information to help individuals make the right decision with their healthcare provider’s guidance.

Women & PI: The Reproductive Years
Patricia Lugar, MD, MS
This session will provide information about becoming pregnant and maintaining pregnancies, treatment considerations before, during, and after pregnancy, and the health histories of children of mothers with PI.

4:45-5:30 PM
Managing GI & PI*
Jodie Ouahed, MDCM, MMSc, FRCPC, FAAP
Learn about the common gastrointestinal issues individuals with PI face, and discover ways to monitor and treat them.

Parenting a Child with PI: A Balancing Act
Christina Mangurian, MD, MAS
This insightful session will focus on family dynamics and the frustrations and rewards of having a family member with PI. Strategies on how to relate to family members, find balance, and create a nurturing environment will be shared.

Life on Your Own: Exclusively for Teens & Young Adults with PI
Brian Rath, JD
The transition to becoming an independent adult can be challenging. Learn from others who have made the transition and ask questions to get answers to help you on your journey.

7:00-8:00 PM
Josh Seth: Virtual Mind Reader & Magician
Joshua Seth is a world touring psychological illusionist, motivational speaker, bestselling author & celebrity voice actor. He has toured the world with his highly successful psychological illusion show, performed live on stage in over 40 countries, had 5 TV specials in South Korea and Japan, and presented in front of 20,000 people at the Mandalay Bay Arena in Las Vegas.

*Presented or captioned in Spanish
SATURDAY, JUNE 26

10:00-10:45 AM
Coffee Chat: Good Morning with IDF
Board of Trustees

11:00-11:45 AM
Peer Connections for International Guests

11:00-11:45 AM (continued)
Leveraging Patient-Reported Data During the COVID-19 Pandemic*
Deepti Deshpande, MD, MPH
Learn how data collected from the COVID-19 pandemic is now being used.

11:00-11:45 AM
Autoimmunity in Immunodeficiency: An Overview
Alice Chan, MD, PhD
Autoimmune conditions frequently cause problems for individuals with PI. This session will provide information about why this occurs and review some of the more common autoimmune issues in the PI community.

12:00-12:45 PM
Employment & PI: What Are My Rights?*
Brian Rath, JD
Learn about your rights in the workplace. Gain knowledge about the Family & Medical Leave Act (FMLA), the Americans with Disabilities Act (ADA), and discuss disclosure.

12:00-12:45 PM
The Senior Years: Managing PI
Roger Kobayashi, MD
With advanced medical treatment, people with PI are living longer lives. Learn about health issues that affect older individuals with PI to help you live life to the fullest and receive optimal care.

12:00-12:45 PM
Diagnosis & Management of Autoimmune Cytopenias in PI
Jolan Walter, MD
Cytopenia occurs when one or more of your blood cell types is lower than it should be. This session will focus on the diagnosis and treatment of autoimmune cytopenias, such as immune thrombocytopenia (ITP), autoimmune hemolytic anemia (AIHA), and autoimmune neutropenia (AIN) in individuals also diagnosed with PI.

12:00-12:45 PM
Genetic Counseling: What to Consider
Morgan Similuk, MS, CGC
Genetic counseling helps translate the results of genetic testing into practical information and enable individuals and families to understand and reach informed decisions regarding family planning. Specific issues for those with a history of primary immunodeficiency diseases will be discussed.

*Presented or captioned in Spanish
SATURDAY, JUNE 26

12:00-12:45 PM (continued)
Primary Ciliary Dyskinesia (PCD) & PI: Sorting Zebras
Stephanie Davis, MD
Michele Manion, PCD Foundation
Both primary ciliary dyskinesia and primary immunodeficiency are rare disorders, and both, often present with recurrent infections and may, at times, be difficult to distinguish clinically. Learn about the similarities and differences of these two diagnoses and how they are treated.

1:00-2:00 PM
Panel Discussion: Plasma Ethics*

2:15-2:45 PM
Farewell Ceremony

Disclaimer
The Immune Deficiency Foundation Primary Immunodeficiency Conference offers a wide array of educational presentations, including presentations developed by healthcare and life management professionals invited to serve as presenters at the conference. The views and opinions expressed by guest speakers do not necessarily reflect the views and opinions of IDF.

The information presented during the conference does not represent, and is not a substitute for, professional services specifically including the practice of medicine or other professional advice. IDF specifically disclaims any personal liability, loss or risk incurred as a consequence of the use and application, either directly or indirectly, of any information presented herein. All individuals should consult their medical or other competent professionals for healthcare, insurance coverage or similar guidance. Each patient’s condition and treatment are unique.

*Presented or captioned in Spanish
Special Sessions & Ongoing Activities

**CLINICIAN EDUCATION PROGRAM SESSIONS**

**Wednesday, June 23**

4:00-5:00 PM
IVIG & SARS-CoV-2 Antibodies: Bridging the Gap

COVID Vaccination in PI Patients

5:00-7:00 PM
IgNS Session: Ig Therapy - Fact or Fiction

**Thursday, June 24**

4:00-5:00 PM
When to Refer Young Adult Patients to an Immunologist

Lung Disease in Patients with PI: Diagnosis & Treatment

**Friday, June 25**

4:00-5:00 PM
Antibiotic Prophylaxis in PIDD

Use of Immunomodulators to Control Immune Dysregulation

**EDUCATION HALL & POSTER HALL**

These halls will be open throughout the conference. Below is a list of live exhibit hours in the Education Hall.

**Wednesday, June 23**

6:00-7:30 PM
(Gold, Silver & Bronze Sponsors and IDF Booths only)

**Thursday, June 24**

Noon-5:00 PM

**Friday, June 25**

Noon-5:00 PM

**Saturday, June 26**

11:00 AM-2:00 PM
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THANK YOU!

For more IDF events, please visit www.primaryimmune.org/events.