Transcription for: Jorey's monthly wrap-up: April 2025

Hello. As April comes to a close I hope you have had an amazing PI awareness month. It provides a worldwide moment to raise awareness and understanding of primary immune deficiency. But before it officially ends, we have some updates to share with you. Next week, the Immune Deficiency Foundation will host more than one hundred and fifty advocates in Washington DC to meet with members of Congress and their staff. It goes without saying that this is a pivotal time of change in DC with many relevant issues impacting our community. Information and activity at the federal level is ever evolving even daily. Regardless of that, we have some critical and important issues to address during advocacy day that will not change. But based on information we received from that effort engaging with legislators, we'll be updating our statement on federal actions likely in May, so just a heads up on that. And one last note about advocacy day, the afternoon of advocacy day after meetings have concluded, we're inviting members of Congress and congressional staff to join us on-site for a viewing of a piece of our documentary, compromised life without immunity.

I started off by wishing you all a happy PI awareness month, so I would be remiss if I didn't remind everyone that tonight, On April twenty fifth, we're hosting a screening of our documentary, Compromised: Life without immunity at seven thirty pm Eastern Time. It will be shown live on the IDF Facebook page, and you can sign up to watch or get more information on our website. At primary immune dot org and click on the documentary on the homepage. And going on right now is an amazing fundraising and awareness event, international, no less, to support the immune deficiency foundation. Connor or CDawg, A highly influential streamer is hosting a Cycleathon. It began on April thirteenth and concludes on April twenty seventh. I can't wait to share the awareness and resources raised for our organization as a result. If nothing has caught your attention yet, please let this one do that.

Only twice a year do we produce the IDF advocate, the national newsletter of the Immune Deficiency Foundation. The spring twenty twenty five edition features articles on the difference between between PI and autoimmunity, updated information on the new IUS classifications, and an inside look into IDF with a profile on Zach Moore, the director and producer of compromised: life without immunity and all IDF podcasts. You can download an electronic version directly from our website or you can request a print version be mailed to you, both free of charge. Just go to primary immune dot org and navigate to resources at the top right, and it will be one of the first resources you see. Something else I need to catch your attention.

Are you signed up to receive IDF updates or alerts via text? If not, you should be. We have completely revamped our SMS program to segment communications based on who you

are and what you want to receive. Simply text IDF to four one zero three two one, six six four seven to enroll, and we will take it from there. I hope you've had a wonderful April, happy early PI awareness week next week, and I look forward to sharing another update in May. And as always, if you need us, our website is always a great place to start to register for events, to reach out to ask IDF, and to find other resources and support. Just go to primaryimmune dot org. Thank you.