CITIZEN

Newsletter – December 2021

Our Mission:
To drive efforts to cure psoriatic disease and improve the lives of those affected.

Colleagues,

I hope that your holiday season is proceeding nicely. Safe, healthy and full of future memories.

As I wind down this week to wrap up and clean out my office, I've taken only a brief moment or two to reflect on both my time with the Foundation and the voluntary health agency industry. I leave the organization in the capable hands of Leah Howard and more importantly, other professional staff and committed volunteers too many to count. The future of the NPF is very bright and our community of patients, providers, volunteers, advocates, caregivers, manufacturers and policy makers will continue to benefit from an accelerating pursuit of our mission.

I've been incredibly fortunate to have served with many exceedingly talented people. Mentors, supervisors, volunteer partners and colleagues who all contributed to my collective experience. That experience has helped me embrace a few principles that have served me well, three of which I'll take the liberty to share:

1. If you go about your work with the best of intentions, it only stands to reason that those you interact with are doing the same thing.
2. Perform in the job you have as if its an audition for the job you want.
3. The amount of time you dedicate to your job is far less important than whether or not "the ship came in".

I wish all of you the best in helping make the ship come in.

l Board of Directors Spotlight - Dr. Larry Green

Dr. Larry Green's initial experience with psoriasis came as a patient when he was in medical school. His psoriasis flare was mild and successfully treated with topicals and cortisone injections into the plaques. Dr. Green said it was this experience which inspired him to pursue dermatology.

Later, as a dermatology resident at the University of California-Irvine his psoriasis returned. He used UVB therapy, and his disease improved. It was during Dr. Green's residency in the early 1990's, he first became involved with the NPF. Dr. Green was the physician liaison to the Orange County Communication Network. After he and his family moved to the DC area in 1995, he remained involved as a support group leader/physician liaison for the DC area. Dr. Green continued to be very active with the Foundation, volunteering for various NPF local and national events. In 2005, former CEO, Gail Zimmerman asked Dr. Green to be the first dermatologist member of the board of directors. Dr. Green served on the board for 9 years, 6 of which were as chair of the Research Committee.

Dr Green also holds or has held multiple leadership positions in many medical societies including the American Academy of Dermatology, the American Society for Dermatologic Surgery, and the Maryland State Medical Society. He has extensive clinical trial experience, especially in psoriasis, and is author or co-author on over 70 peer reviewed medical publications.

In June 2020 Dr. Green was re-appointed to the board of directors and Chair for the NPF Research Committee. Dr. Green said, "NPF is the premier patient advocacy organization in the country. I am amazed how much it has grown from just a grass roots patient awareness organization to being a trendsetting organization that funds millions of dollars in research grants a year while advocating relentlessly for people with psoriasis in Washington DC and even every state's legislature.

For me, advocating for legislation that will benefit my patients (on behalf of the NPF) is the most satisfying part of my work with the NPF. I also very much enjoy learning about and seeing the types of research grants the NPF awards and how I hope they will ultimately help people with psoriasis."

Dr Green serves as a Clinical Professor of Dermatology at the George Washington University School of Medicine in Washington DC. Dr. Green resides in Rockville, Maryland with his wife Allison. His adult children are currently living abroad.

l Mission Moment

This month, our Mission Moment comes from Paige Glover:

"Dr. Alpesh Desai is a dermatologist here in Houston who owns Heights Dermatology. He also just recently acquired Dr. Menter's practice (who has long supported the NPF). He was introduced to me in 2020 by one of my Novartis reps. Since the introduction he has jumped head first into supporting the NPF by sponsoring the Pstamp Out events in Houston and Dallas (2021), sponsoring the Houston Walk (2021), and fundraising for the Houston Walk (2020 and 2021). In 2020, he personally raised $6,138 for team Heights Dermatology (for a virtual event!), and quickly set his sights higher for the 2021 walk, raising $22,130! This is more than any other team in the Houston Walk history that I can find and helped us more than double our original goal for Houston Walk 2021. He did this by challenging all of his vendors, family and friends to support his efforts. He shared with me that he is passionate about giving back and his mother's autoimmune disease sparked that at a young age. He practices here in Houston, but also travels throughout South Texas helping derm patients through charity work."

l Special Events and Field Services

Bingo Winner

Christine Ramig,
Mission Moment speaker

Pstamp Out Psoriatic Disease

November 18
St. Louis Pstamp Out

Run with Team NPF in Chicago on October 9, 2022!

We have been accepted in the Chicago Marathon again this year and have 7 spots remaining. Registration is open until January 31, 2022.

CITIZEN - DECEMBER 2021

Strategic Alliances

December was a busy month for the corporate partnership team! Here are some highlights:

- We've raised over $1.7M.
- Corporate membership renewals from Novartis, BIO, Boehringer-Ingelheim
- Patient education grants for the Volunteer Conference, Journal Club and Youth Ambassador
- CME funding including APREP and Grand Rounds

Principal & Planned Giving

- Received $1.1 million in pledges for our upcoming predictive model research program, which is the 3rd leg of our strategic plan research stool.
- In cooperation with Individual Giving, several new marketing initiatives are scheduled in 2022 for our new Stock Gift and Planned Giving tools.
- Began preparations for our March 20, 2022 Major Donor cultivation event in Florida.
- Successfully received a Major Gift of land in Chicago, which is now for sale.

Individual Giving

Giving Tuesday Update: We raised $51k during the Giving Tuesday campaign. This campaign included an email strategy to continue engagement from World Psoriasis Day as well as segmented email targeting to those who received the direct mail appeal. We sent a series of emails on Nov. 23 and concluded the campaign on Nov. 30 with morning, afternoon, and even-ing messages. Additionally, we incorporated Stock Monday messaging on Nov. 29 and a matching gift challenge throughout Giving Tuesday.

Holiday Campaign: Following Giving Tuesday and for the remaining weeks of 2021, we re-introduced our Holiday Campaign, utilizing social media and frequent e-appeals to help us reach our Holiday campaign goals. These appeals included a farewell video from Randy and an anonymous matching gift challenge.

Many thanks to the MarComm, Principle Giving and Data Management teams whose hard work and collaboration were instrumental in the success of this campaign.

AmazonSmile: We would like to remind all staff when you shop on AmazonSmile and add NPF as your charity of choice, 0.5% of your eligible Amazon purchases will be automatically donated to NPF. Just remember to shop through smile.amazon.com and be sure to turn on amazon smile on your mobile app.

Marketing & Communications

The next issue of NPF Advance magazine hits mailboxes in early January 2022. The theme is "Reaching Milestones" and includes a special feature about the Psoriasis Prevention Initiative (PPI).

The marketing team continues to partner with the individual giving team to support the 2021 holiday fundraising campaign. The campaign theme is "This is NPF," and it features stories of individuals from the psoriatic disease community who have been helped by NPF programs and services, as well as a special message from Randy (click on image to view).

Finally, the marketing team is pleased to continue its campaign to promote the new CME podcast feed. Since beginning this new marketing campaign, listens to CME podcasts have increased, supported by increased messaging on NPF channels, as well as partner messaging through The Dermatologist and native advertising on the Yahoo network.

Patient Services

PNC Highlights: The PNC ended the year with a campaign focusing on Self-Advocacy. The kit contains 4 resources, *Diagnosing Psoriasis*, *Diagnosing Psoriatic Arthritis*, *Flare Guide & Symptom Tracker* and *Making a Treatment Decision*. The goal of the campaign is to help people become better advocates for themselves and their health. As of Dec. 23 there have been 158 requests for the kit. Campaigns over the Christmas holidays tend to have fewer requests. Since July 1, the PNC has served 9,647 constituents through 16,181 interactions.

Volunteer Services: Planning continues for the NPF 2022 Community Conferences. Please mark your calendars for the next virtual conference scheduled for March 5, 2022. Jenn Pellegrin will be hosting and there are already sessions scheduled on topics including Advocacy, emotional resilience with Stevie Dawn Blakley, PhD and PsO issues unique to women and men.

The first in person conference since 2019 will be held on April 30, 2022 in Chicago. Tyler Lewis will be our master of ceremonies and there will be a youth track and special programs for children/youth. Jonathan Scott (NPF Board member) and Dr. Amy Paller will be a part of the conference.

Psound Bytes™: As of Dec. 17 total overall listens over 101 patient episodes is 99,510. We ended the year with another Gold Standard episode, *Over-the-Counter Products and Tips for Managing Scalp Psoriasis*, with Tirsa Quartullo, DNP.

Strategic plan FY20 – FY24 Goals:

1: Lead collaborative, transformational research in psoriatic disease.
2: Increase the lifespan and health of individuals living with psoriatic disease.
3: Secure the human, technological, and financial resources necessary to achieve the NPF's mission-related goals.

Volunteer Spotlight - Caroline Williams

Caroline Williams of Portland, Oregon grew up in the United Kingdom. As a child, her family moved frequently, including spending several years in Cardiff, Wales. Caroline studied English and American Literature at Kent University in Canterbury, England and, following graduation, moved to Spain where she lived and worked for a year. Linguistics has always been a fascination for Caroline who became fluent in Spanish during her time there.

In the early 80's Caroline worked for a Computer Lease & Rental company in London when the company transferred her and a colleague to establish a branch in New York City. During the next decade, Caroline married, moved several times and had 5 children within 10 years, finally settling in Northern Virginia.

Caroline has had several careers throughout her life, including founding a non-profit in 1989 called Mother's Access to Careers at Home "MATCH". She said "trying to balance my career and family was insane. I became a fanatic about mothers having flexible schedules" noting that the technology existed, even then, for women to work remotely. Caroline became an active advocate, writer, and spokesperson for remote work, co-authoring a book in 1999 (Moneymaking Moms; How Work at Home Can Work for You) and leveraged the media to promote her message, including appearances on network and local TV and in various print articles.

Caroline was diagnosed with scalp psoriasis in the early 2000s, following an intense period of duress. After several years of struggling (and failing to improve) with topical treatments, she was fortunate to find a dermatologist who prescribed biologics; an experience she describes as "life changing".

In August of 2018, she returned to the United Kingdom to care for her ailing mother. She also had to confront the challenges (rather unsuccessfully) of getting the care and medications she needed through the UK's National Health Service (NHS). In 2020, Caroline moved back to the United States and relocated to Portland, Oregon to be close to her son, Jake. Fortunately. she is now back on biologics and doing much better!

Caroline has been volunteering with NPF for a year. Initially, she worked with the Research and Medical Team on an outreach project verifying the contact information of providers and clinics. In September 2021, she started as an admin volunteer in the Patient Navigation Center in Portland. In a short time, Caroline has become an integral part of the team, sending out literature and samples as well as Our Spot Welcome kits to constituents. Jane Slayden said, "It is a joy to have Caroline come in each week to help Patient Services. She is always cheerful and has a devilish sense of humor."

When Caroline isn't busy working or volunteering, she enjoys exploring Portland. Her daughter lives in Seattle so trips to Washington are frequent. She also enjoys crossword puzzles, reading and experimenting in the kitchen.

Research & Medical Programs

Research Updates

Bridge Grant: Our 1st cycle of Bridge grant applications were reviewed and approved for funding by our Research Committee on Dec. 13. We received the most applications to the Bridge grant program than any previous cycle. Funding was approved for Dr. Siba Raychaudhuri's application entitled "Total body PET/CT imaging biomarkers for diagnosing and quantifying inflammatory burden of psoriatic arthritis" for $100,000 in additional funding.

NIAMS K-Forum (photo right): Our Research Team participated in the NIAMS K-Forum on Dec. 6 and 7. The forum is hosted by NIAMS every year and bring together current early career clinician researchers that are funded by the NIH with mentors, NIAMS program staff, and representatives from professional voluntary organizations to talk about how to support this demographic in establishing themselves as independent clinical investigators. One of our past NPF-funded fellows, Cory Simpson, is a current NIAMS K-awardee and was also in attendance at the symposium discussing his research in inflammatory disease.

ISPOR: NPF was represented at ISPOR 2021 serving as a moderator/speaker in partnership with the National Health Council to present the Patient Experience Mapping project.

Medical Affairs

Psound Bytes CME: December was a busy month! The Medical Education team produced 4 podcasts to close out the year with 18 episodes! This month we're featuring episodes on New Frontiers in Psoriatic Disease Research Part 2 (based on a SAC paper), managing aging populations, family planning, and a Dermatology/Rheumatology Collaborative events recap. In addition, the new feed is live as well as the new Media Center for Health Care Providers webpage.

APReP: On Dec. 9, the NPF - along with the Rheumatology Nurses Society and NYU Langone Health - jointly presented a virtual Psoriasis and Psoriatic Arthritis CME Program for Nurses, Advanced Providers, and Trainees. Eileen Lydon, MA, ANP-BC and Veronica Richardson, NP, MSN, CRNP, ANP-BC brought their respective expertise in dermatology and rheumatology to this informational program.

Shared Management: On Dec. 13, Drs. Evan Siegel and Ronald Prussick virtually presented Psoriatic Disease Shared Management - discussing treatments that address both joint and skin symptoms, examining differential diagnosis, comorbidities, and reviewing how to apply a collaborative care and shared management model for the treatment of patients with psoriatic disease.

Our Core Values

Individuals living with psoriasis and psoriatic arthritis are at the center of everything the NPF pursues. NPF has always supported innovative approaches to treating psoriasis and psoriatic arthritis. With a perspective that through partnership and collaboration greater achievements are possible, the NPF has advanced research efforts towards finding a cure and improved health access challenges to dramatically improve the health outcomes of all affected by psoriasis and psoriatic arthritis.

Government Relations & Advocacy

As we approach the close of 2021, we extend to you our warmest wishes. We hope you have enjoyed a healthy and joy filled holiday season!

The Advocacy team celebrated the holidays by joining patients and providers volunteers for our annual holiday party. We had a great time virtually ringing in the season with stories, 2021 recaps, and excitement about the opportunities ahead in the new year.

As we reflect on the last year, the NPF advocacy team wants to take a moment to look back on our shared successes and look forward toward 2022. It goes without saying that 2021 has been a hectic year in healthcare policy. However, thanks to your partnership and that of others in our space, we've been able to accomplish great things at both the state and federal levels. We appreciate your generous assistance, and we look forward to working together to expand access to care in 2022. Enjoy our 2021 in review!

Action to ensure "All Copays Count!": The NPF mission is "to drive efforts to cure psoriatic disease and improve the lives of those affected." Many of the initiatives pursued by the advocacy team are aimed at improving the lives of our community today by expanding access to treatments. One of the biggest frustrations for patients—and their providers—is new policies that make it harder to access their treatments.

In 2021, we saw expanded adoption of copay accumulator adjustment programs. Insurers that use these programs accept copay assistance for expensive medications without counting this assistance towards a patient's cost-sharing obligations, draining patient assistance funds only to leave their beneficiaries on the hook for thousands of dollars in sudden bills that patients rarely see coming.

Working with partners, NPF successfully advanced commonsense reforms to help protect patients from copay accumulators. Seven states passed accumulator reforms in 2021, bringing the total number of states with patient protections against this practice to twelve (plus Puerto Rico). We expect to see similar bills in state legislatures across the country in 2022 and hope to build on the successes of 2021! In D.C., Illinois and Oregon, legislation was introduced in 2021 but did not make it across the finish line. While the bills in D.C. and Illinois are currently under review, we are working on strengthening our approach to reintroduce the bill in Oregon. NPF hopes to raise the issue of accumulator adjustment programs in new states while strengthening our connections in the states where proposed reforms are being taken up for a second or third time.

More recently, NPF has also played a role in fighting to pass legislation that would address this issue at the federal level. In November, we told you about the HELP Copays Act of 2021, which would protect patients from accumulators by requiring health plans to count copay assistance towards a patient's cost-sharing requirements. Since then, the NPF advocacy team has worked with our coalition partners to champion this bill and tapped into our grassroots network to build popular support for it. Over 200 community advocates have already written to their lawmakers about this bill using NPF's Action Alert Portal, and NPF plans to facilitate more grassroots engagement on this important bill in 2022.

Step Therapy: Not even a pandemic could slow our efforts to pass step therapy reform in 2021. This year, we moved beyond the halfway tipping point—more than half of all U.S. states now have step therapy guardrails in place.

As NPF works to educate policymakers and advocates in those states in which we have not yet passed bills, we have continued to note that our collective efforts on this topic have not sought an outright ban on step therapy, but rather commonsense guardrails that let patients and providers bypass step therapy protocols where they are clearly inappropriate for the patient's health.

2021 was a big year for our efforts to pass step therapy reform, with wins in several states across our Western and Central regions. Arkansas led the way as the first state in 2021 to legislate reform. Nebraska, Oregon, and Arizona all followed. One of our biggest wins on this issue occurred in early October, when California passed CA AB 347 into law. In addition to our advocacy team's hard work and leadership in California, NPF's volunteer advocates also did an amazing job of helping this bill across the finish line. A special shout out goes out to our patient volunteer Jenn Pellegrin for testifying on her personal experiences with step therapy. Looking forward to 2022, NPF hopes to build on our successes in California by expanding those protections to include Medical, the state's Medicaid program. We also hope to continue our momentum by passing additional step therapy protections in states without existing legislation such as Florida, Massachusetts, and Utah, as well as expanding upon existing legislation in states such as Colorado and Maryland.

We have also seen some movement on step therapy at the federal level. The House and Senate have both taken up versions of the Safe Step Act of 2021, which would establish guardrails on the practice to ensure that patients and physicians can bypass step therapy wherever it would be inappropriate for the patient's health. The Safe Step Act has been introduced during previous sessions of Congress without ever coming up for a floor vote, but NPF remains committed to championing this legislation and looks forward to moving the ball forward on this iteration of the bill in 2022.

Calendar of Events

Date	Event	Guest Speaker/Presenter/CDM	Format	Location
2/20	Team NPF Run/Austin Marathon Half Marathon and 5k	Kris Bockmier, kbockmier@psoriasis.org	In-person	Austin, Texas
3/5	NPF Community Conference	Audrey Riggs, ariggs@psoriasis.org	Virtual	TBD
4/5	Pstamp Out in Austin	Kris Bockmier, kbockmier@psoriasis.org	In-person	Austin, Texas
4/7	Pstamp Out in Birmingham	Chuck Thomaselli, cthomaselli@psoriasis.org	In-person	Birmingham, Alabama
4/30	NPF Community Conference	Audrey Riggs, ariggs@psoriasis.org	In-person	Chicago, IL

Visit www.psoriasis.org/calendar and www.psoriasis.org/watch-and-listen for more information and updates.