

# Forging Ahead

Over 1 Million Grants Awarded



# Health Care Access and Cost Issues Emerged as COVID Waned: HealthWell Foundation Continued to Forge Ahead

As we imagine a world without COVID...without cancer, hepatitis, multiple sclerosis, cystic fibrosis and other chronic and life-altering illnesses...we know that tens of thousands of underinsured Americans still need our help every day. These individuals are your family, friends, and co-workers. They teach your children, staff your favorite stores and restaurants, protect your communities, and care for you when you're sick or need help.

They are the reason why HealthWell will continue to forge ahead in our mission to help the underinsured access critical medical treatments – because no one should go without essential care because they cannot afford it.

Toward the close of 2021, Americans reported a growing struggle to pay for health care. In fact, 30 percent polled in a 2021 survey did not seek treatment for a health problem due to its cost.

Adults who are in worse health are twice as likely than those with better health to delay or go without care due to cost reasons.

Source: Peterson-KFF Health System Tracker

As the acuteness of the COVID-19 pandemic began to wane, thousands in the country still felt its impact every day, in new infections, hospitalizations, and the relentless toll of losing friends and loved ones. And while our economy started to get back on track, some businesses couldn't recover, leaving laid-off employees scrambling to afford basic necessities, including health care.

38 million Americans (15%) said they had greater difficulties paying for health care in 2021 due to the pandemic.

Source: West Health-Gallup 2021 Healthcare in America Report

Despite over 90 percent of the U.S. population having health insurance, the steadily increasing cost-sharing burdens people must bear are driving them into financial distress. In 2021, nearly half (47%) of insured adults reported difficulty affording their out-of-pocket costs, and one in four (27%) reported difficulty affording their deductible. Among Medicare beneficiaries, more than five million struggled to afford prescription medications.

30 percent of Americans are concerned about being unable to pay for prescription drugs.

Source: West Health-Gallup 2021 Healthcare in America Report

For people with a chronic illness, even small copays and other costsharing expenses can accumulate to unaffordable amounts, especially since most households' savings are less than the maximum out-ofpocket limit allowed for most private insurance plans.

Roughly 20% of US households report having medical debt.

Source: Consumer Financial Protection Bureau

We understand far too well what happens when people are forced to make hard decisions between affording medical treatments and paying daily living expenses. We understand what happens to their families and their futures when they are forced to declare bankruptcy. That is why we feel so fortunate to make a difference in their lives – to forge ahead with our mission in even the bleakest of times.

### Letter from our President and Board Chair

In 2021, health care challenges remained firmly fixed in America's consciousness as the COVID-19 pandemic waxed and waned. More people than ever learned what it was like to live with a life-altering disease – how quickly it can upend their daily lives, relationships, finances, and futures. As access to care continued to present challenges for America's underinsured, the need for our services continued to grow.

We understand all too well the devastating impact a health care crisis can have on families, forcing them to make difficult decisions whether to pay rent, buy food, pay for basic daily necessities or fill their prescriptions. That is why we are honored to provide a financial lifeline to those who have nowhere else to turn, and why we are beyond grateful for the support of our dedicated individual and corporate donors who allow us to carry out our mission.

The continued trust and support our donors place in us is a testimony to the high ethical standards with which we have, and will continue to, run our programs. Operating in full compliance with federal guidance that governs the copayment assistance industry is the cornerstone of our operations. The way we are structured, governed, and operated is the ethical and right thing to do, and we wouldn't have it any other way.

In 2021, we were honored to achieve a significant milestone of awarding our one millionth grant. We were proud to have launched or re-opened 18 funds, including a HealthWell-sponsored COVID-19 Frontline Health Care Workers Behavioral Health Fund. We also continued to operate more than 60 funds, including multiple funds in oncology and special initiative funds in behavioral health and pediatrics. None of this would have been possible without the continued generosity of our individual and corporate donors.

On behalf of our board of directors and dedicated corporate and contact center teams, we would like to close by thanking our donors, our provider and pharmacy networks, our patient advocacy organization partners, our devoted employees, and especially our patients. We would also like to send a special thank you to our nation's frontline health care workers for their compassion, commitment and tireless efforts to keep us safe and healthy. We are profoundly grateful for your unwavering commitment to assisting those in need.

Warmest regards,

Kirsta Zodet

Warm wishes,

Krista Zodet President Stephen M. Weiner Board Chair

Styla M. Weiner

## Words of Thanks and Gratitude

"We want to express our profound gratitude for honoring my husband, Tom, by awarding him a \$15,000 grant to support him through his journey with ALS. Tom was formally diagnosed with ALS on August 3, 2017.



**Nelly & Tom** 

ALS has robbed us of life as we knew it, including Tom losing his speech, his mobility, and his livelihood. However, it has not robbed him of his mind, heart, sense of humor, or the example he sets for others.

The words in this note speak from both of our

hearts. In the face of overwhelming adversity, we have strived to live through Tom's ALS diagnosis with grace and dignity. While he has also been hospitalized dozens of times, Tom wishes to live life to its fullest and in our home. Consequently, the progression of his disease required me to quit work to become his full-time caregiver. Without any paychecks coming in, our savings have been depleted by relentless medical bills and ongoing household expenses. Your grant to pay for Tom's insurance has been a lifeline and a blessing to our family during this difficult time. With sincere gratitude, we thank you."

#### **Nelly L., wife of Tom**

(Amyotrophic Lateral Sclerosis (ALS) Grant Recipient)
Sanford, Florida



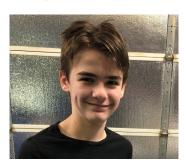
Bill

"I want to thank you for the grant you've awarded me for treatment of my Dupuytren's Contracture. I'm a musician and this issue has had an impact on the quality of my playing and, as a result, the quality of my life, for many years. Your gift will

help significantly. Thank you very much."

#### Bill H.

(Dupuytren's Disease Fund Grant Recipient) Yellow Springs, Ohio "Our son, Jadon, was in an advanced food allergy program to desensitize him from foods that caused dangerous anaphylactic reactions. However, our insurance refused



Jadon

to cover his ongoing remission appointment and testing, which coincided with the Covid pandemic. Covid flattened our small business, and we scrambled to save our business and our household while trying to get Jadon the care he needed.

HealthWell to the rescue! Jadon got all of the testing and the appointment he needed. He's progressing in his remission and found medical information that will improve the effectiveness of his maintenance. There has been a weight lifted and we are so glad to be done with this part of things! Our gratitude is large. Many, many thank-yous."

#### Abby S., mother of Jadon

(Pediatric Fund Grant Recipient)
Santa Clarita, California

"Thank you so much for helping fund my medication. Due to Chronic Lymphocytic Leukemia (CLL), my lymph nodes grew and started to cut off my trachea and esophagus, making it



John

difficult to breathe and eat. I had to sleep sitting up.

After prayer and an infusion, my lymph nodes quickly went back to normal. Then they started growing again. I was prescribed medication, but it was not affordable at \$13,000 a month. Because of

the medication your grant helped provide, I won't have to worry about CLL shutting my throat and leaving me feeling claustrophobic. If you can imagine feeling the fear of your throat closing in, and then not feeling like that, you get an idea of my level of thankfulness for what you are doing for me."

#### John H.

(Chronic Lymphocytic Leukemia (CLL) Grant Recipient)
Haw River, North Carolina

## HealthWell Foundation 2021 Achievements

Thanks to individual and corporate contributions of \$538,184,808 in 2021, the HealthWell Foundation provided financial assistance to 175,695 patients and reached the milestone of awarding 1,117,805 grants since 2004. We were proud to:

- Award \$818,446,309 in medication copayment and insurance premium assistance through 185,493 grants<sup>1</sup> to underinsured Americans.
- Launch a HealthWell-sponsored
   COVID-19 Frontline Health Care
   Workers Behavioral Health Fund,
   providing grants of up to \$2,000 to
   assist frontline health care workers
   in covering their out-of-pocket
   treatment-related copayments for
   prescription drugs, counseling services,
   psychotherapy, and transportation
   needed to manage COVID-19 related
   behavioral health issues.
- Provide financial assistance to
   1,174 children living with chronic or life-altering conditions through the HealthWell Pediatric Assistance Fund®.
- Assist 134 oncology patients seeking behavioral health services through our Cancer-Related Behavioral Health Fund.
- Strengthen the diversity and number of our individual donor base to over 63,500 donors with more than 17,000 giving in 2021.

- Maintain operational efficiency by programming our grants with an overhead rate of <2.61% foundationwide, while never using any donor dollars to pay administrative fees.
- Launch a Spanish-language
   application, expand content on our
   Español page, and create a new version
   of our Disease Funds list in Spanish.
- Increase our social media presence, growing our online audience to over 9,800 followers, resulting in over 3.2 million impressions, almost 33,000 engagements, and over 16,100 clicks.
- Increase our Real World Health Care blog following to 18,879 users and 25,691 page views.
- Spread our message nationally with dozens of alliance partners, resulting in close to 684 million media impressions from placements in major news outlets.
- Welcome David F. Ertel to the Foundation's Board of Directors.
- Enhance our staff with the addition of two new corporate team members.

<sup>1.</sup> Some eligible patients receive grants through more than one fund during the year.

### Who We Assist - The Lives We Touched in 2021

#### Age Breakdown

8% · under 35 | 3% · 35-49 | 11% · 50-64 | 78% · 65+

Marital StatusGender47% Single54% Female53% Married46% Male

#### **Top 10 States Assisted**

Florida | Texas | California | Ohio | New York Pennsylvania | North Carolina | Georgia Illinois | Tennessee

#### **Top Five Disease States**

By Grant Approval Volume

16% Hypercholesterolemia

14% Post Menopausal Osteoporosis

13% Multiple Myeloma

8% Prostate Cancer

5% Pulmonary Hypertension

#### **Referral Sources**

35% Pharmacy

28% Provider/Physician/Nurse/Advocate

**10**% Reimbursement Support Line/Manufacturer

**10**% Another Copay Foundation (Patient Assistance Program)

5% Case Manager/Social Worker

3% Disease-Specific Non-Profit/Patient Support Organization

3% Patient/Family Member/Caregiver

3% Other

2% Website/Web Search

1% Private Insurer (i.e., BCBS, United)

#### Household Size Breakdown

32% One person (58,466)

56% Two people (104,250)

5% Three people (9,564)

7% Four or more people (12,402)

#### Household Income Breakdown

\$33,000 Median Household Income

**43**% of patients' household income is under \$30,000

\$30,000 was 172% of the FPL for a household of 2

62% of patients' household income is under\$40,000

40,000 was 230% of the FPL for a household of 2

**84**% of patients' household income is under **\$60,000** 

\$60.000 was 344% of the FPL for a household of 2

#### **Greatest Need**

85% of patients need up to \$7,700

10% of patients need \$8,900+

\$3,218 Average grant amount in 2021

2% Proportion of assistance requests for premium

37,691 Monthly average number of calls handled

# HWF Direct, LLC – Forging Ahead: Compassionate, Responsive and Quality Care

Since 2018, our dedicated contact center, HWF Direct, LLC, has had a mission to provide unparalleled, compassionate customer service through innovative cloud-based solutions and an empowered, dedicated staff. Our strength as a team sets us apart from other contact centers. Providing the highest quality customer service and ensuring that our specialists take the time needed to resolve caller issues within the first contact is our number one priority.

As the need for HealthWell's services continued to grow, we expanded our team with close to 50 new members in 2021. As a result of this growth, HWF Direct now consists of nearly 150 highly-trained, mission-driven professionals who serve as the first line of communication for those who reach out to us for assistance.

Our key performance metrics focus on providing compassionate, responsive, and quality care to each and every caller, and our high performance has been applauded by patients, providers and pharmacies.

#### During 2021, our dedicated contact center team:

- Received 491,911 calls through our hotline while maintaining a call capture rate of 93.5%.
- Maintained a 98% staff retention rate, with 95% of staff working remotely for the majority of 2021.
- Completed an organizational restructuring to reflect our patients' journey and to ensure frontline staff have a support system of subject matter experts.
- Promoted a Program Director and expanded our Leadership Team to support frontline staff.
- Streamlined multiple processes to improve our ability to provide a compassionate, compliant, and completely satisfactory experience for those we serve.
- Enhanced our Quality Assurance evaluation and auditing process.
- Created 186,438 grants (including withdrawn and cancelled grants<sup>1</sup>) via the hotline, online applications, and portal.
- · Responded to:
  - 134,264 copay reimbursement/payment requests with an average processing time of less than seven business days.
  - 15,850 premium reimbursement/payment requests with an average processing time of less than three business days.
  - 39,357 email questions/requests with same day response time.
- Completed over 3,918 internal audits/reviews of our handling of calls, payments, and other tasks, demonstrating that we are successfully meeting our internal standards for providing a compassionate, compliant, and completely satisfactory experience 93% of the time.





More than 37,000 callers assisted each month



Actively managed over 185,400 grants



Average monthly calls handled by IVR: 17,826



Calls into hotline: 491,911



Calls handled by specialists: 238,337



Average inbound call capture rate: 93.5%



Average call talk time: 8–10 minutes



<sup>1.</sup> Creating a grant results in operational activity whether it is used, unused, cancelled, or withdrawn.

## Our Commitment to Compliance and Transparency

Like other independent charitable patient assistance programs (CPAPs), the HealthWell Foundation receives the majority of its donations from the pharmaceutical industry. As a result, HealthWell is structured, governed and operated in compliance with federal legal and regulatory requirements and is required to operate independently from our corporate donors.

HealthWell, as with other CPAPs, is subject to oversight by the U.S. Department of Health and Human Services, Office of Inspector General (OIG), whose mission is to protect the integrity of federal health care programs. The OIG provides strict guidance for how CPAPs should be structured to maintain compliance with these requirements.



HealthWell has and will continue to operate under strict compliance best practices and follow OIG guidance to the letter, as illustrated above. Maintaining compliance, independence, and transparency has been our standard operating policy since our inception and is essential to our ability to serve our mission.

Our transparency and efficiency continue to receive external recognition, and in 2021 we were honored to:



Rank 27th on Forbes' 2021 list of the 100 Largest U.S. Charities. Be recognized by Forbes as one of only 13 charities nationwide to achieve a 100 percent fundraising efficiency rating.



Score 100 out of 100 on Charity Navigator's Encompass Rating System.



Be awarded the 2021 GuideStar Platinum Seal of Transparency.



Rank as a 2021 Top-Rated Charity by GreatNonProfits.



Be recognized by Chronicle of Philanthropy as one of America's Favorite Charities.



Rank #37 on NonProfit Times 2021 Top 100.

## 60+ Funds Covered a Variety of Disease Areas

In 2021, the HealthWell Foundation continued to operate more than 60 funds in a variety of disease areas, including multiple funds in oncology and our special initiative funds in behavioral health and pediatrics. We launched or re-opened

18 funds, including new funds to assist Medicare patients living with Myelodysplastic Syndromes, Neurocognitive Disease with Psychosis, Pancreatic Cancer and Pulmonary Hypertension.

HealthWell was proud to provide financial assistance to the families of over 1,170 children living with chronic or life-altering conditions through our HealthWell Pediatric Assistance Fund® in 2021. We also assisted 53% of public health workers reported symptoms of at least one mental health condition in 2021.

Source: Centers for Disease Control and Prevention

more than 130 oncology patients seeking behavioral health services through our Cancer-Related Behavioral Health Fund.

#### **Helping Frontline Health Care Workers Cope**

Traumatic events can have serious, long-term effects on mental wellbeing, and accessing mental health care was a challenge in 2021, especially for those in the health care industry. In fact, 18 percent of frontline health care workers thought they needed mental health care services or medications last year but did not get them. For 16 percent of those who did not seek such care, it was because of cost.

"We applaud the HealthWell Foundation for recognizing the paramount need for frontline health care workers who are going to heroic measures to save the lives of those impacted by COVID-19 by providing a vital financial resource that will enable them to obtain critical behavioral health services."

#### **Susan Gurley**

Executive Director, Anxiety and Depression Association of America

HealthWell recognized the unmet needs of frontline health care workers and launched the COVID-19 Frontline Health Care Workers Behavioral Health Fund to provide assistance for behavioral health treatments for those who have been impacted by the COVID-19 health crisis.

#### **Funds Open During 2021**

- Acromegaly
- Acute Myeloid Leukemia
- Adrenal Insufficiency
- Amyloidosis
- Amyotrophic Lateral Sclerosis
- ANCA-Associated Vasculitis, and Granulomatosis with Polyangiitis (formerly Wegeners)
- Asthma
- Bladder and Urothelial Cancer Medicare Access
- Bone Metastases Medicare Access
- Breast Cancer Medicare Access
- · Cancer-Related Behavioral Health
- Chemotherapy Induced Neutropenia Medicare Access
- Chronic Heart Failure Medicare Access
- Chronic Lymphocytic Leukemia
- · Chronic Myeloid Leukemia Medicare Access
- Colorectal Carcinoma Medicare Access
- · Congenital Sucrase-Isomaltase Deficiency
- COVID-19 Frontline Health Care Workers Behavioral Health
- COVID-19 Insurance Premium Payment Assistance
- · Cushing's Disease
- Cystic Fibrosis Treatments
- Cystic Fibrosis Vitamins and Supplements
- Cytomegalovirus Disease Prevention and Treatment
- · Dupuytren's Disease
- Giant Cell Arteritis or Temporal Arteritis -Medicare Access
- Gout Medicare Access
- Gout Travel Fund
- Head and Neck Cancer Medicare Access
- Hepatitis C
- Homocystinuria
- Hypercholesterolemia Medicare Access
- Hyperoxaluria
- Immunosuppressive Treatment for Solid Organ Transplant Recipients-MedicareAccess
- Lambert-Eaton Myasthenic Syndrome
- Macular Degeneration (Wet and Dry)
- · Mantle Cell Lymphoma
- · Melanoma Medicare Access
- Movement Disorders Medicare Access
- Multiple Myeloma Medicare Access
- Multiple Sclerosis Medicare Access
- Myelodysplastic Syndromes Medicare Access
- Neurocognitive Disease with Psychosis -Medicare Access
- Non-Small Cell Lung Cancer Medicare Access
   Non-type regularia Magazine Medicare
- Nontuberculous Mycobacterium Medicare Access
- Ovarian Cancer Medicare Access
- Pancreatic Cancer Medicare Access
- Pediatric AssistancePevronie's Disease
- Porphyrias
- Post Menopausal Osteoporosis Medicare
   Access
- Prostate Cancer Medicare Access
- Pulmonary Fibrosis
- Pulmonary Hypertension Medicare Access
- · Renal Cell Carcinoma Medicare Access
- Secondary Hyperparathyroidism
- Sickle Cell Disease
- Small Cell Lung Cancer Medicare Access
- Systemic Lupus Erythematosus
- Tardive Dyskinesia Medicare Access
- Urea Cycle Disorders
- Urticaria
- Wilms' Tumor

Accote

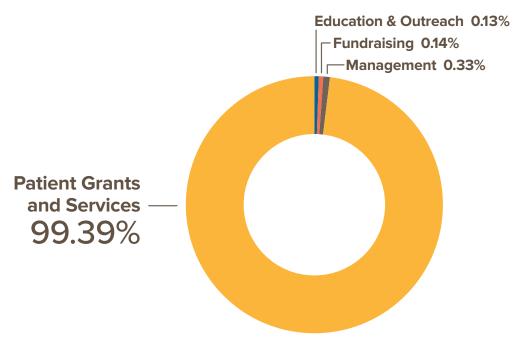
# Statement of Financial Position

# Revenue and Expense Summary

TOTAL LIABILITIES & NET ASSETS	\$ 529,554,117	
Total Net Assets	\$ \$504,315,707	
Temporarily Restricted	444,626,419	
Unrestricted	\$ 59,689,288	
Net Assets		
Total Liabilities	\$ 25,238,410	
Deferred Rent	158,574	
Copayments and Premium Assistance Payable	7,178,295	
Accounts Payable and Accrued Expenses	\$ 17,901,541	
Liabilities		
Liabilities and Net Assets		
Total Assets	\$ 529,554,117	
Property and Equipment, net	632,237	
Pledges Receivable	29,995,974	
Interest Receivable and Other Assets	702,521	
Investments	392,476,920	
Cash and Cash Equivalents	\$ 105,746,465	
Assets		

Expense Ratios		
Patient Grants and Services		99.39%
Management		0.33%
Fundraising		0.14%
Education and Outreach		0.13%
Revenue		
Donations and Other Income	\$ 5	38,184,808
Investment Income	\$	13,714,191
Total Revenue	\$5	51,898,999
_	\$5	51,898,999
Expenses		,
_		<b>51,898,999</b>
Expenses		,
Expenses Patient Grants and Services	\$ 6	25,887,689
Expenses Patient Grants and Services Management	\$ 6	25,887,689

# 2021 Expenses



## **Board of Directors**

## 2021 Staff Listing

Stephen M. Weiner

**Board Chair** 

Founding Chair, National Health Law Practice Mintz, Levin, Cohn, Ferris, Glovsky and Popeo PC

Jerri M. Scarzella, BSN

Vice Chair & Treasurer Policies & Procedures Coordinator Holy Cross Health (Retired)

David L. Knowlton

Vice Chair, Secretary & Chief Compliance Officer
President & CEO, NJ Health Care Quality Institute (Retired)

Cathleen D. Bennett, Esq.

President & CEO

New Jersey Hospital Association

Nancy Carteron, MD, FACR

Health Sciences Clinical Professor Herbert Wertheim School of Optometry & Vision Science University of California, Berkeley Clinical Professor of Medicine (Volunteer) University of California, San Francisco

David F. Ertel

Chief Financial Officer Vizient, Inc.

Don Liss, MD

Vice President and Chief Medical Officer Horizon Blue Cross Blue Shield of New Jersey

Suzanne M. Miller, PhD

Professor, Cancer Prevention and Control Program Director, Patient Empowerment and Decision Making Department

Fox Chase Cancer Center/Temple University Health System

Scientific and Ethics Advisor

Jeffrey Peppercorn, MD, MPH

Director

Massachusetts General Hospital Supportive Care and Survivorship Program Associate Professor of Medicine Harvard Medical School Krista Zodet

President

Alan Klein

Chief Development Officer

Shela Halper

Senior Foundation Program Officer

Collin Alexander

Director of Finance

Fred Larbi

**Director of Operations** 

**Ginny Dunn** 

Senior Associate Director Communications & Marketing

Jeremy Abbundi

Associate Director External Relations

Erica Mata

**Associate Director of Operations** 

**Tim Vawter** 

Associate Director Information Technology

**Sharon Flores-Britt** 

Senior Accountant

Rita Coleman

Senior Operations Manager

**Crystal Lynch** 

Senior Manager, External Relations

**Brian Katz** 

Manager, Development and Individual Giving

**Cesar Martinez** 

Solutions Architect

**Sarina Robbins** 

Development Support Manager

**Lorrin Rosen** 

Human Resources Manager

Samuel Sappor

Data Analytics Manager

Chelsea Lingrel

**Digital Strategist** 

Albert Mejia

Junior Accountant

Franck Dewonou

**Operations Support Coordinator** 

Sabrina Howard

Office Assistant

Maya Larbi

Marketing Assistant



HealthWell Foundation 20440 Century Boulevard Suite 250 Germantown, MD 20874

#### www.HealthWellFoundation.org

Addressing a critical need, the HealthWell Foundation is an independent 501(c)(3) charitable organization dedicated to reducing financial barriers to care for underinsured Americans with chronic and life-altering medical conditions. HealthWell is a financial lifeline for adults and children who desperately need critical medical treatments but can't afford them. We help patients pay their share of prescription copayments, deductibles, health insurance premiums, and other ancillary costs. By reducing their financial stress, the people we serve can focus on what's most important: their health.

- PHONE: (240) 632-5300
- FACEBOOK: Facebook.com/healthwellfoundation
- INSTAGRAM: @HealthWellFoundation
- TWITTER: @HealthWellOrg
- YOUTUBE: HealthWellFoundation
- in LINKEDIN: healthwell-foundation

HealthWell Foundation Financial Reports

