2022-2023

ANNUAL REPORT

| WWW.MEACTION.NET |

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1 LETTER

to the #MEAction Community

TO THE #MEACTION COMMUNITY

This past year has been filled with so many wins, so many good things. It's also been filled with a lot of grief for our community, and particularly #MEAction. As we go into this next year of activism, education, and awareness, we are also prioritizing support for our community. Each and every one of you matters more to us than you will ever know.

We are using our grief to fuel us into the next year as we evolve #MillionsMissing to directly interact with a clinical audience to improve patient care, as we train a new cohort of volunteers to support one another through Canary Corps, as we continue to collaborate with large medical institutions like the Mayo Clinic, as we work inside and outside of federal agencies to increase ME studies, funding, and education, as we hold space for the community in our support groups and activities, and as we train new volunteers to join our fight for change.

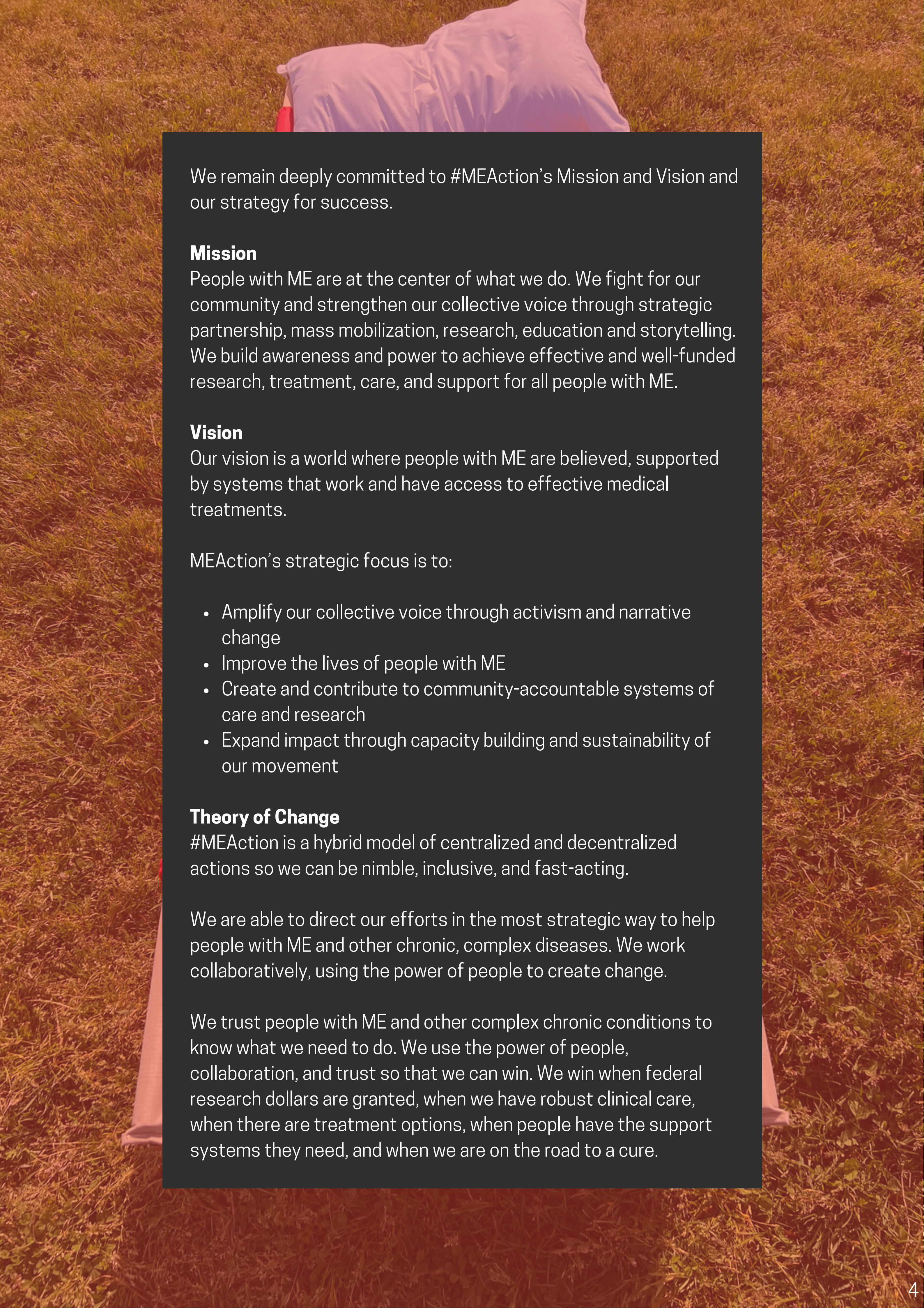
We are passionate about creating change for people with ME. You, as always, are at the heart of what we do. With you, beside you, we fight together for you.

In solidarity and with gratitude,

All of us at #MEAction
Laurie, Ben, Jaime, Erin, Adriane, Holly, Steven, Shalida, Marynka, and board members Jennifer, Jill, Judy, Kehsi Iman, Michelle, Niranjan, Robert, Ryan, and Shaquile

2

STRENGTHENING OUR COMMITMENT TO FIGHT



We remain deeply committed to #MEAction's Mission and Vision and our strategy for success.

Mission
People with ME are at the center of what we do. We fight for our community and strengthen our collective voice through strategic partnership, mass mobilization, research, education and storytelling. We build awareness and power to achieve effective and well-funded research, treatment, care, and support for all people with ME.

Vision
Our vision is a world where people with ME are believed, supported by systems that work and have access to effective medical treatments.

MEAction's strategic focus is to:

- Amplify our collective voice through activism and narrative change
- Improve the lives of people with ME
- Create and contribute to community-accountable systems of care and research
- Expand impact through capacity building and sustainability of our movement

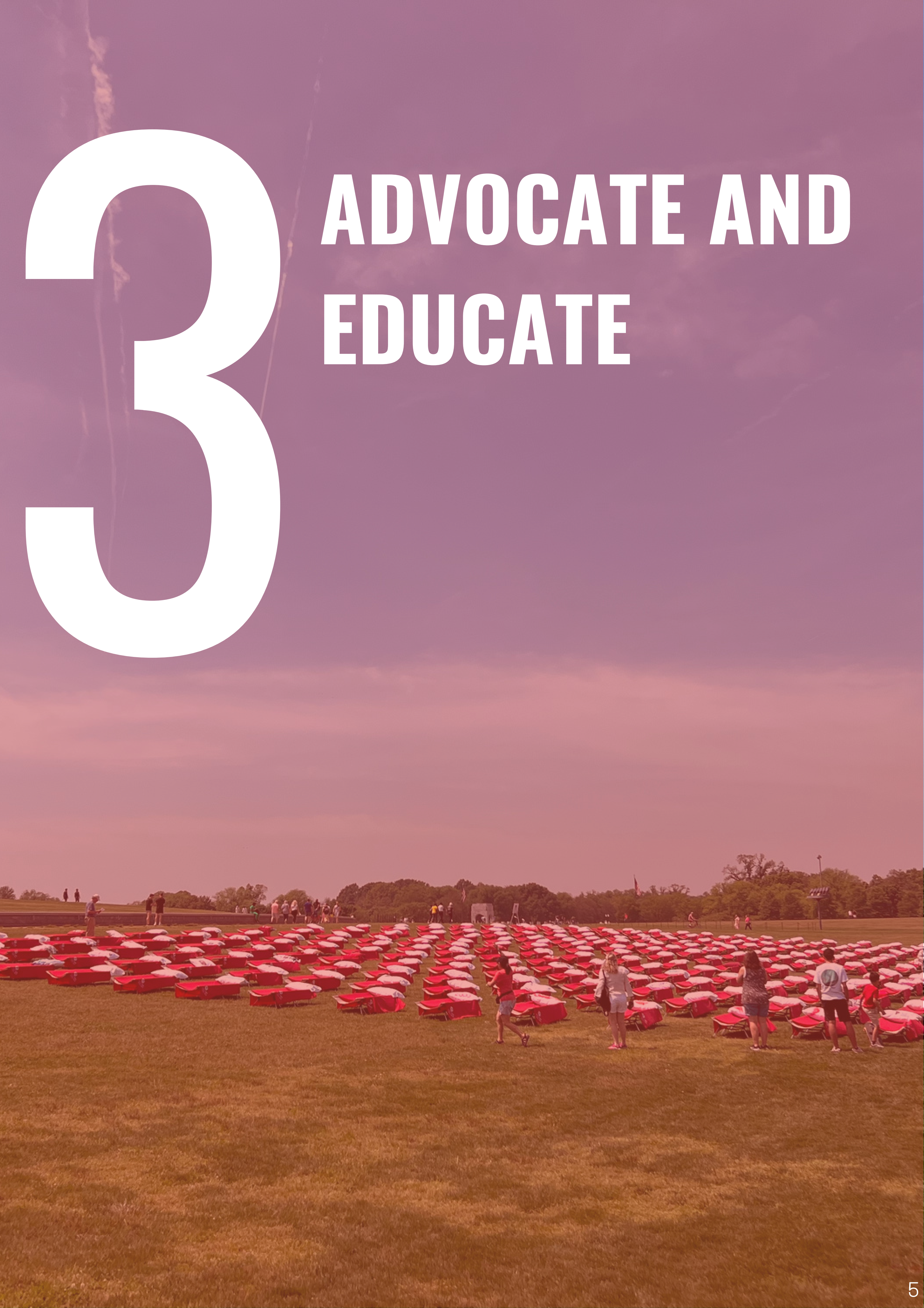
Theory of Change
#MEAction is a hybrid model of centralized and decentralized actions so we can be nimble, inclusive, and fast-acting.

We are able to direct our efforts in the most strategic way to help people with ME and other chronic, complex diseases. We work collaboratively, using the power of people to create change.

We trust people with ME and other complex chronic conditions to know what we need to do. We use the power of people, collaboration, and trust so that we can win. We win when federal research dollars are granted, when we have robust clinical care, when there are treatment options, when people have the support systems they need, and when we are on the road to a cure.

3

ADVOCATE AND EDUCATE



Massive Art Installation on the Mall

#MEAction’s protest in front of the White House in 2022 garnered an enormous amount of press coverage including The New York Times, The Hill, Medscape and so many more, which led #MEAction to put together a massive art installation in Washington, D.C. in 2023. On our national Mall, we set up 300 beds covered in red blankets with personalized pillowcases to represent the millions of people with ME and Long COVID. People from both communities decorated 300 pillowcases with their stories and art to demonstrate the experience of ME and Long COVID, which we displayed on the beds. Now, the installation lives on through an online gallery where you can see stories, pictures, and videos of the event itself. Watch a video about the art installation.

Social media blew up with praise for the art installation on the Mall. Here are just a couple things people had to say:

- “The 2023 protest was breathtaking and emotional to see. A play from the disability justice playbook, centering those who are most affected. A way to include those literally suffering in silence.”

- “I’m thankful for the hard work that @meactnet does to keep this issue at the forefront and demand recognition and funding. I won’t call myself an activist quite yet, but for the first time I feel part of the larger national movement for change because my pillowcase was part of the #MillionsMissing protest in D.C. As always, thank you for your love and support. It means so much to me!”

ME and Long COVID

This year, Body Politic became a program of #MEAction to align our goals with those of the Long COVID community. Body Politic was one of the leading support groups for Long COVID with over 14,000 members. We've worked with Alison Sbrana, a person with ME who helped lead Body Politic's support group, to design a new initiative called Canary Corp which will connect people with ME and Long COVID to local disability services and supports.

"I am passionate about helping chronically ill and disabled people understand and access disability supports, because after living with ME for almost 10 years myself, the most life-changing intervention has been accessing these services myself so I can stop/rest/pace and have my daily needs met."

~ Alison Sbrana

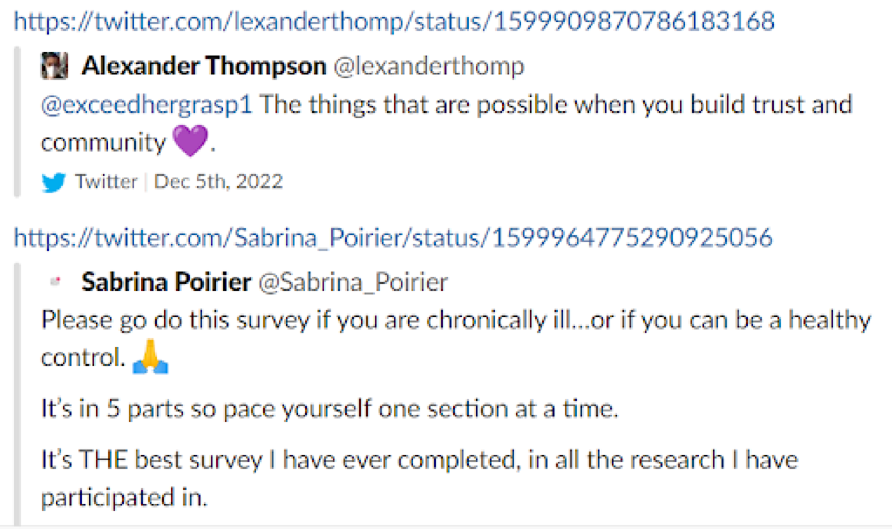
State Chapters

#MEAction State Chapters have been busy locally and federally to continue the fight for ME and Long COVID recognition and awareness. While the road is long and often filled with delays and detours, #MEAction State Chapters continue to drive forward and make inroads:

- #MEAction NH hosted a large-scale event at Dartmouth College to educate health practitioners about ME. They were featured heavily in the local press!
- #MEAction Maryland delivered books about ME to every member of Congress to continue to educate them on ME and what can be done to improve the ongoing neglect.
- #MEAction Colorado offered emergency services support for local people with ME who need assistance.
- #MEAction Minnesota has been diving deep into state advocacy.
- #MEAction New York has big plans for January 2024 (coming soon)
- #MEAction Georgia hosted a virtual book reading with Ryan Prior and Elizabeth Weaver for their their book The Long Haul
- #MEAction California continued their education and advocacy efforts and all state chapters participated virtually in #MillionsMissing.

The Chronic Illness Survey Adventure

This year, we completed The Chronic Illness Survey Adventure - a massive survey aimed at providing clinicians and researchers with key data that could educate and generate better care for and quicker diagnoses of ME and other chronic diseases. Our hope is that the survey will identify aspects of the disease that are well understood by patients, but not as well understood by the clinicians who see them and the researchers who want to learn more. We have over 2200 complete responses to all 5 parts of the survey, giving us terrific data to analyze in 2024!



https://twitter.com/lexanderthomp/status/1599909870786183168

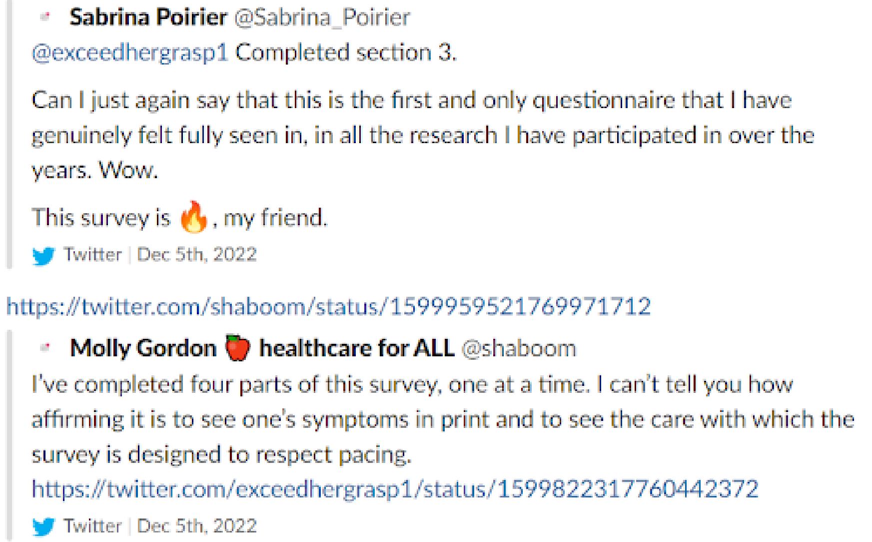
Alexander Thompson @lexanderthomp
@exceedhergrasp1 The things that are possible when you build trust and community 💜.
Twitter | Dec 5th, 2022

https://twitter.com/Sabrina_Poirier/status/1599964775290925056

Sabrina Poirier @Sabrina_Poirier
Please go do this survey if you are chronically ill…or if you can be a healthy control. 🙏

It's in 5 parts so pace yourself one section at a time.

It's THE best survey I have ever completed, in all the research I have participated in.



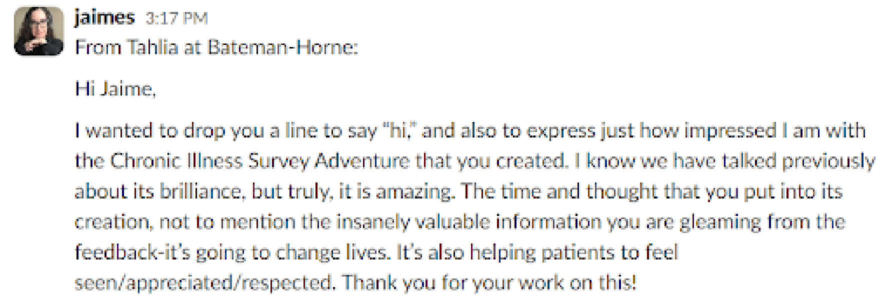
Sabrina Poirier @Sabrina_Poirier
@exceedhergrasp1 Completed section 3.

Can I just again say that this is the first and only questionnaire that I have genuinely felt fully seen in, in all the research I have participated in over the years. Wow.

This survey is 🔥, my friend.
Twitter | Dec 5th, 2022

https://twitter.com/shaboom/status/1599959521769971712

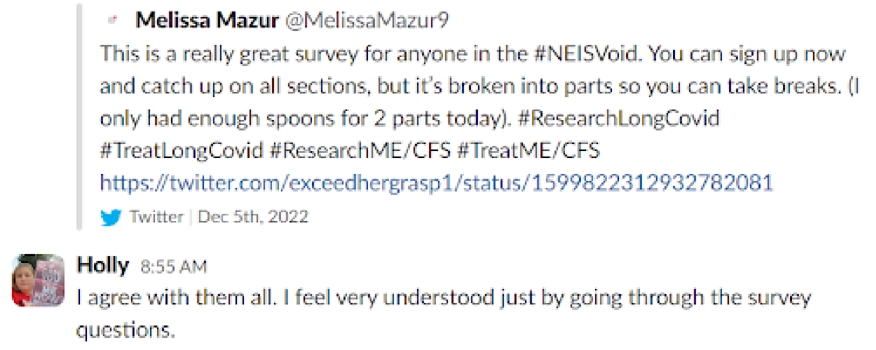
Molly Gordon 🍎 healthcare for ALL @shaboom
I've completed four parts of this survey, one at a time. I can't tell you how affirming it is to see one's symptoms in print and to see the care with which the survey is designed to respect pacing.
https://twitter.com/exceedhergrasp1/status/1599822317760442372
Twitter | Dec 5th, 2022



jaimes 3:17 PM
From Tahlia at Bateman-Horne:

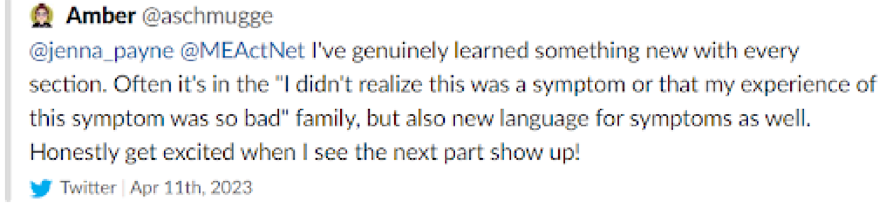
Hi Jaime,

I wanted to drop you a line to say "hi," and also to express just how impressed I am with the Chronic Illness Survey Adventure that you created. I know we have talked previously about its brilliance, but truly, it is amazing. The time and thought that you put into its creation, not to mention the insanely valuable information you are gleaming from the feedback-it's going to change lives. It's also helping patients to feel seen/appreciated/respected. Thank you for your work on this!



Melissa Mazur @MelissaMazur9
This is a really great survey for anyone in the #NEISVoid. You can sign up now and catch up on all sections, but it's broken into parts so you can take breaks. (I only had enough spoons for 2 parts today). #ResearchLongCovid #TreatLongCovid #ResearchME/CFS #TreatME/CFS
https://twitter.com/exceedhergrasp1/status/1599822312932782081
Twitter | Dec 5th, 2022

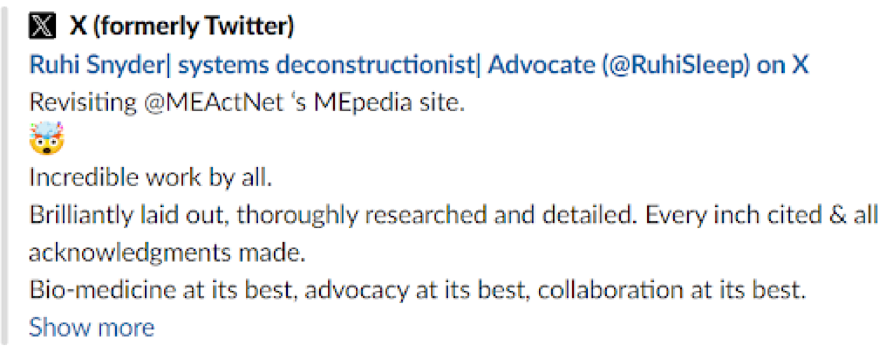
Holly 8:55 AM
I agree with them all. I feel very understood just by going through the survey questions.



Amber @aschmugge
@jenna_payne @MEActNet I've genuinely learned something new with every section. Often it's in the "I didn't realize this was a symptom or that my experience of this symptom was so bad" family, but also new language for symptoms as well. Honestly get excited when I see the next part show up!
Twitter | Apr 11th, 2023

MEpedia Revamp

In 2023, #MEAction transformed MEpedia through a generous grant. Our MediaWiki developer for the project updated MEpedia's software and will provide ongoing technical support. An accessibility expert recommended changes before we finalized our new design, including fresh graphics and a clean layout for our landing page. Now we are translating some of our most vital articles into other languages and updating our content on COVID and Long COVID. We have reached over 25 million people through MEpedia!



X (formerly Twitter)

Ruhi Snyder| systems deconstructionist| Advocate (@RuhiSleep) on X

Revisiting @MEActNet 's MEpedia site.
🤯
Incredible work by all.
Brilliantly laid out, thoroughly researched and detailed. Every inch cited & all acknowledgments made.
Bio-medicine at its best, advocacy at its best, collaboration at its best.

Mayo Clinic Project

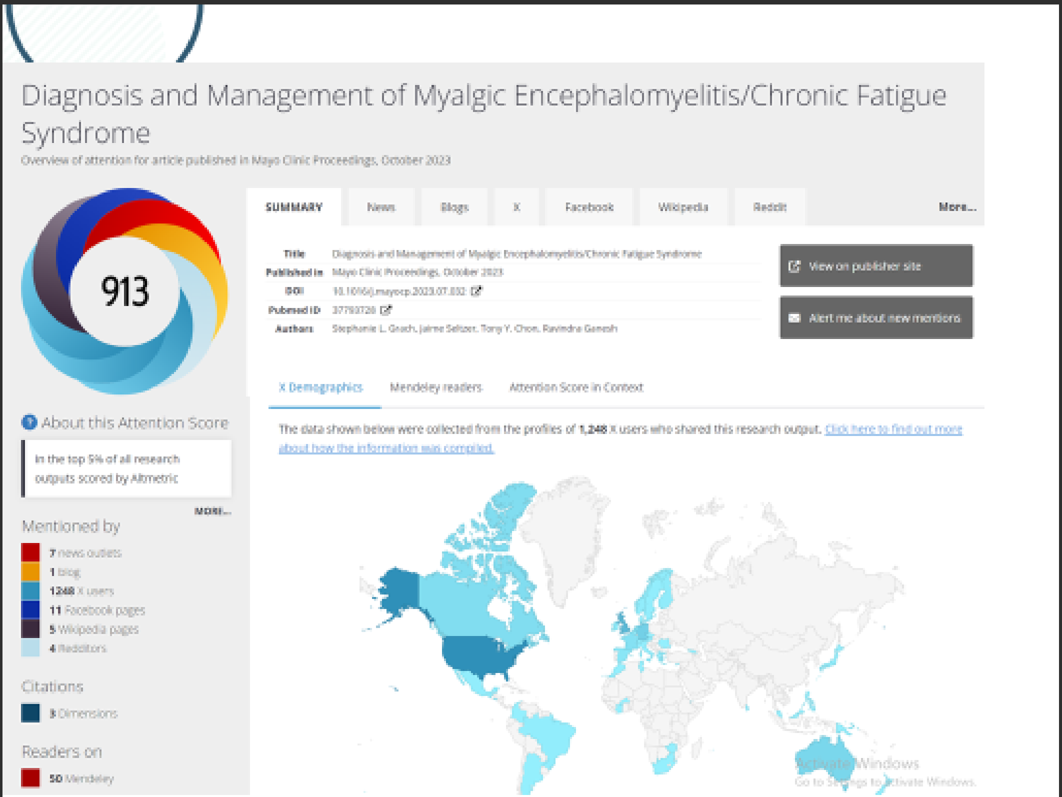
Our Scientific Director applied for and received a grant from the Society to Improve Diagnosis in Medicine (SIDM) with Mayo Clinic Rochester clinicians Dr. Ravindra Ganesh and Dr. Stephanie Grach. #MEAction used this seed grant to produce:

- A new, **public-facing page on ME/CFS** at Mayo
- A new **diagnostic and treatment algorithm** within AskMayoExpert, available to all Mayo Clinic staff and Mayo subscribers. It is one of the only such to address severe ME.
- A Concise Clinical Review in Mayo Clinic Proceedings, with an associated one-credit CME, with beautiful and information-rich graphics, a description of ME in minoritized populations, and a description of severe ME.

In addition, we have applied for and received funding for a new project with Mayo Clinic Rochester for 2024 and written an additional paper on treatment guidance that will debut this year. This successful project also strengthened our pre-existing relationship with SIDM, who was impressed with the ultimate impact of our grant-funded work both around the world and at our respective organizations. In part due to this work, Mayo Clinic Rochester is in discussions regarding a new ME/CFS clinic, and our work with Mayo has gone on to shape our approach to #MillionsMissing this year, with potential partnerships at many major medical schools and hospital systems.

The Concise Clinical Review was well-received, with an Altmetric Score in the 900s. In order to be in the top 100 papers of the year, an Altmetric score over 500 is typically required, and the higher the better– making this paper one of the most talked-about of 2023. It’s in the top 5% of all research outputs of any kind (papers from any publication, ever), and is the 19th most talked-about paper to ever come out of the journal Mayo Clinic Proceedings, or the top 0.3%. It’s in the top 1% for papers about its age from any publication. It has been cited in three new papers so far and seven news articles so far.

In addition, our work with Mayo has led to our #MillionsMissing theme of 2024: Teach ME, Treat ME. We hope to use our work with Mayo Clinic Rochester as a model for parnership with other hospital systems and medical schools.



Diagnosis and Management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Overview of attention for article published in Mayo Clinic Proceedings, October 2023

Title	Diagnosis and Management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
Published in	Mayo Clinic Proceedings, October 2023
DOI	10.1016/j.mayocp.2023.07.032
Pubmed ID	37793728
Authors	Stephanie L. Grach, Jaime Seltzer, Tony Y. Chon, Ravindra Ganesh

About this Attention Score

In the top 5% of all research outputs scored by Altmetric

Mentioned by

🟥 7 news outlets
🟧 1 blog
🟦 1248 X users
🟦 11 Facebook pages
⬛ 5 Wikipedia pages
🟦 4 Redditors

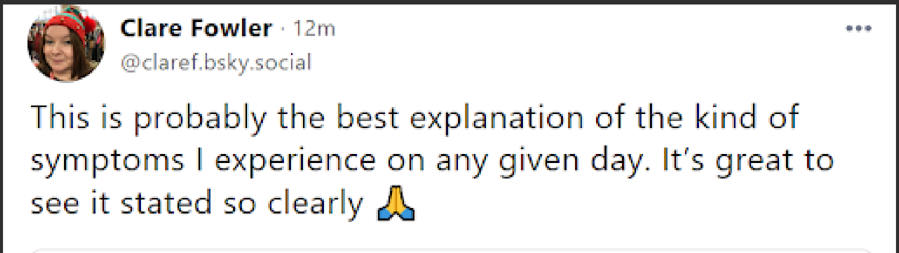
Citations

🟦 3 Dimensions

Readers on

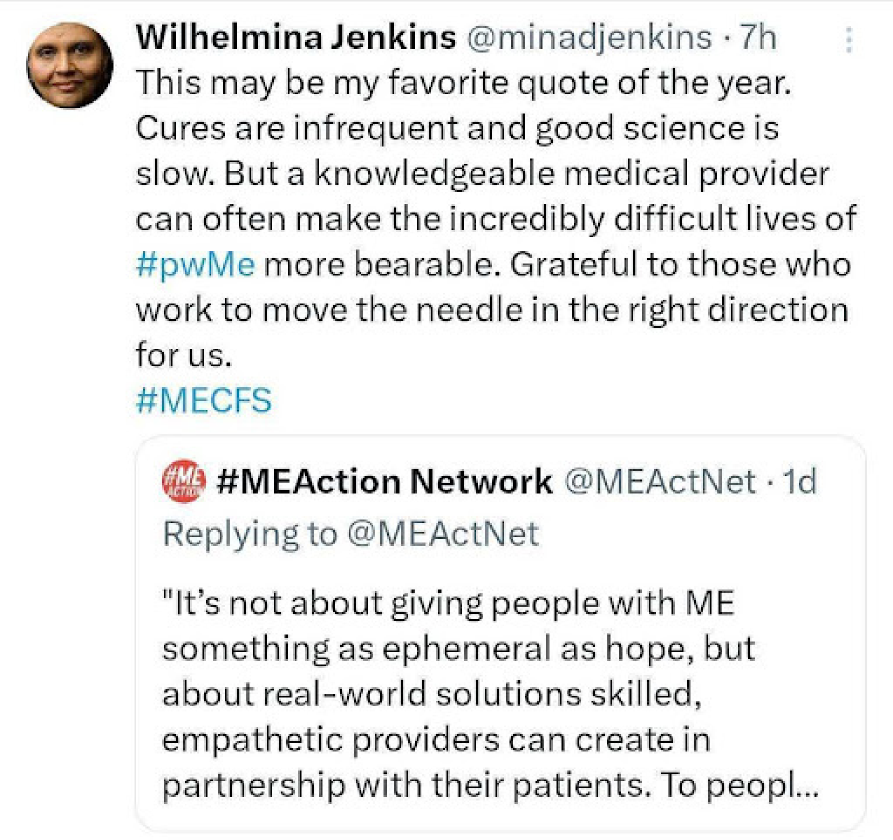
🟥 50 Mendeley

The data shown below were collected from the profiles of **1,248** X users who shared this research output. Click here to find out more about how the information was compiled.



Clare Fowler · 12m
@claref.bsky.social

This is probably the best explanation of the kind of symptoms I experience on any given day. It's great to see it stated so clearly 🙏



Wilhelmina Jenkins @minadjenkins · 7h

This may be my favorite quote of the year. Cures are infrequent and good science is slow. But a knowledgeable medical provider can often make the incredibly difficult lives of #pwMe more bearable. Grateful to those who work to move the needle in the right direction for us.
#MECFS

#MEAction Network @MEActNet · 1d
Replying to @MEActNet

"It's not about giving people with ME something as ephemeral as hope, but about real-world solutions skilled, empathetic providers can create in partnership with their patients. To peopl...

Dakota @Dakota_150 · Oct 17, 2023

[whispers to self] I only hope to make as positive of an impact someday that these two rockstars just dished out with this great work. Really, this is narrative-changing, barrier-reducing output.

Kudos, @exceedhergrasp1 @GrachStephanie

#MEAction Network @MEActNet · Oct 17, 2023

In case you missed it, check out the video that accompanies the publication of the *Mayo Clinic Proceedings paper* on how to diagnose & manage #MECFS.

Jaime Seltzer and Dr. Stephanie Grach share their insights! ...
Show more

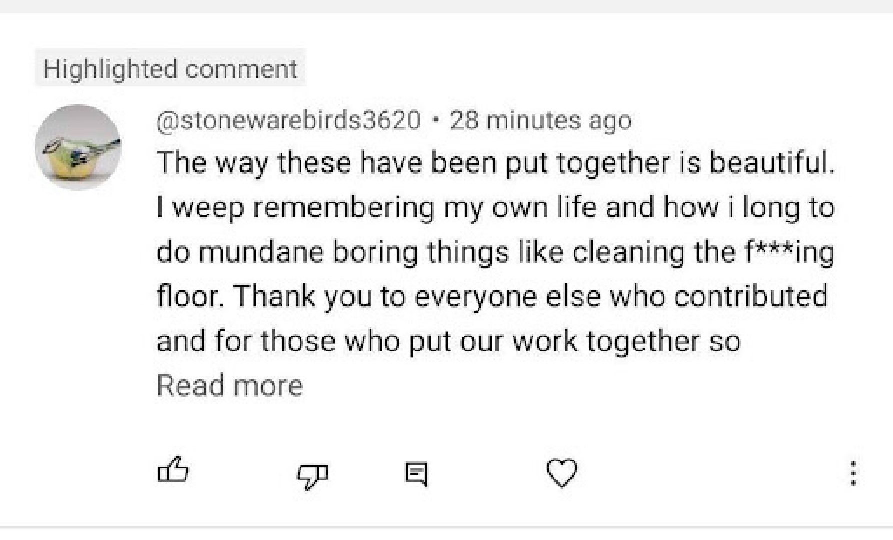
Federal Agency Work

#MEAction's Ben HsuBorger and Jaime Seltzer joined a broad advocacy discussion in Long COVID and infection-associated chronic illness with the Commissioner of the FDA, Dr. Robert Califf, in 2023. As an outgrowth of this broader discussion, Scientific Director Jaime Seltzer and the co-founder of Patient Led Research Collaborative, Hannah Davis, met with the CMO of the FDA, Hilary Marston, to engage in a discussion of validated endpoints for drug trials for ME/CFS and Long COVID.

Press

#MEAction continues to be very prominent in the press, getting featured in major news outlets and keeping ME in the conversation around Long COVID and infection-associated chronic illnesses. Some highlights include our Stat News article on NIH's recover program; providing context for ME in Times Union about the connection between ME and an overproduction of protein; and an article in the Sick Times about how changing a US census survey could artificially reduce the number of disabled people in the U.S., and what that means for the ME community.

Severe ME Artists Project
In August of 2023, #MEAction hosted our third annual, Severe ME Artist Project. This project was created with an idea to allow those with severe ME to share their artwork with the larger community and provide an opportunity to be SEEN! This year's project featured over 130 artists and includes pieces that were created both before and after people became severely ill. The project showcased heartwarming work in the writers' gallery, art gallery, and video gallery. All of the amazing pieces were put together in a moving compilation video.



@stonewarebirds3620 • 28 minutes ago

The way these have been put together is beautiful. I weep remembering my own life and how i long to do mundane boring things like cleaning the f***ing floor. Thank you to everyone else who contributed and for those who put our work together so

Writing, Reading, Supporting, and Connecting
#MEAction is always looking for new ways to bring our community together. Recognizing that our community is filled with so many creative individuals, we have continued to host our Artists' and Writers' Salons. Where people gather to share their art and writings. The Writers' Salon features members of the Pillow Writers group which has now blossomed into a major artistic group, featuring multiple groups meeting weekly and the Pillow Crafters group.

Beyond the art, #MEAction has been able to offer a very modified movement (yoga) class in partnership with Nourish Therapeutic Yoga. This class offers breathing exercises, gentle movement, and meditation and was created for people with ME by a person living with ME. Our community continues to find great reward in participating in these classes as they may not be something they would be able to find on their own.

In all, the #MEAction community enjoys the profound opportunities provided to them to find connection in our humanity. To be able to feel seen, cared for, and understood.


mell34211 8h

@meactnet really got tears in my eyes, because it has been so long since i was able to do yoga and never have been able to join 'normal' classes now for years- so thank you for providing this and also the recording. Where can i find it, later on?

Social Media
#MEAction reaches many thousands through strategic use of social media. Our community organizes, supports, fundraises, socializes, shares news, and finds another on social media. It is a critical part of our ability to fulfill our mission and vision. #MEAction is maintaining active accounts on Facebook, Instagram, LinkedIn, X (Twitter), YouTube, and TikTok and BlueSky. We continue to prioritize our 6,000+ strong Living with ME group and worked hard to build and grow the many other support groups we offer, like Pregnancy and Parenting with ME, Seniors Connect groups, and Long COVID. We have prioritized safety in our groups and have paired them down to those with volunteer moderators to help assist in keeping them an inclusive, safe, and welcoming place for our community to go to find needed support. Every day of every year, our mandate is to help people find support, build community, and take action knowing that the fight to improve the lives of people with ME is far from over. Social media is vital to our mission and how we operate.

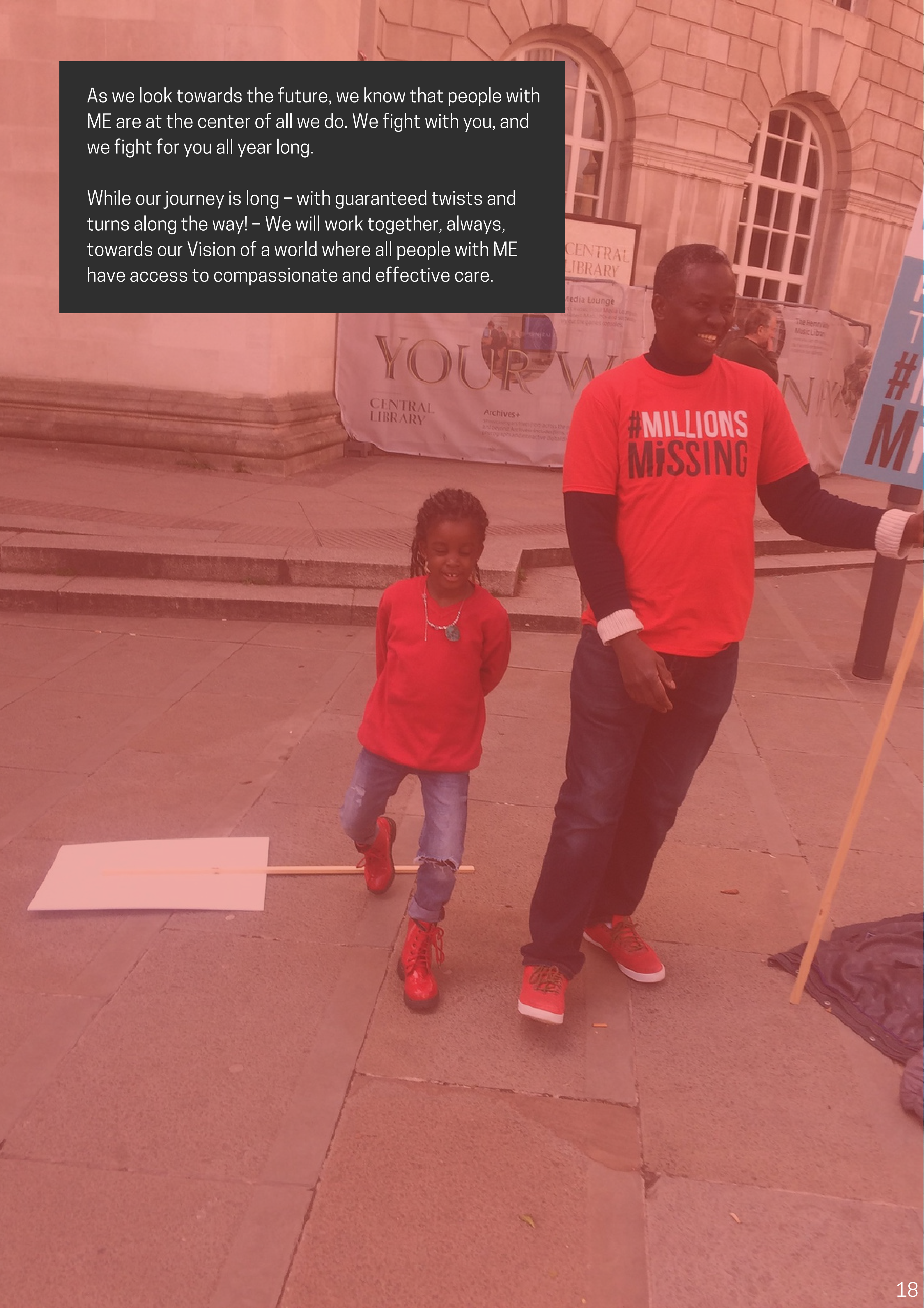
Volunteer Pipeline Easier Than Ever!
It's easier now for volunteers to get involved with #MEAction! We have different working groups that let volunteers utilize their skills with different staff members. One of the groups is our Volunteer Social Hour that meets on Wednesdays. This group works on becoming an advocate for themselves and others. It also teaches ways to be more inclusive in the disability rights community. Volunteers are able to volunteer while still having their individual accommodations met. Our volunteers are the backbone of our organization and it's so important to me that their needs are met and we are making sure our organization prioritizes diversity and inclusion.

4

LOOKING TO THE FUTURE

As we look towards the future, we know that people with ME are at the center of all we do. We fight with you, and we fight for you all year long.

While our journey is long – with guaranteed twists and turns along the way! – We will work together, always, towards our Vision of a world where all people with ME have access to compassionate and effective care.



5

FINANCIALS

Report of Independent Auditors

The Board of Directors
The Myalgic Encephalomyelitis Action Network

Report on the Audit of the Financial Statements

Opinion

We have audited the financial statements of The Myalgic Encephalomyelitis Action Network ("MEAction"), which comprise the statements of financial position as of September 30, 2022, and the related statements of activities and changes in net assets, functional expenses, and cash flows, for the year then ended, and the related notes to the financial statements.

In our opinion, the accompanying financial statements present fairly, in all material respects, the financial position of MEAction, as of September 30, 2022, and the changes in its net assets, functional expenses, and cash flows for the year then ended, in accordance with accounting principles generally accepted in the United States of America.

Basis for Opinion

We conducted our audits in accordance with auditing standards generally accepted in the United States of America ("U.S. GAAS"). Our responsibilities under those standards are further described in the Auditor's Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of MEAction and to meet our other ethical responsibilities, in accordance with the relevant ethical requirements relating to our audit. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Responsibilities of Management for the Financial Statements

Management is responsible for the preparation and fair presentation of the financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, that raise substantial doubt about MEAction's ability to continue as a going concern within one year after the date that the financial statements are available to be issued.

Auditor's Responsibilities for the Audit of the Financial Statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and therefore is not a guarantee that an audit conducted in accordance with GAAS will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control. Misstatements are considered material if there is a substantial likelihood that, individually or in the aggregate, they would influence the judgment made by a reasonable user based on the financial statements.

In performing an audit in accordance with GAAS, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.
- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and design and perform audit procedures responsive to those risks. Such procedures include examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of MEAction's internal control. Accordingly, no such opinion is expressed.
- Evaluate the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluate the overall presentation of the financial statements.
- Conclude whether, in our judgment, there are conditions or events, considered in the aggregate, that raise substantial doubt about MEAction's ability to continue as a going concern for a reasonable period of time.

We are required to communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit, significant audit findings, and certain internal control–related matters that we identified during the audit.

Moss Adams LLP

Rancho Cordova, California
November 6, 2023

The Myalgic Encephalomyelitis Action Network
Statement of Financial Position
September 30, 2022

ASSETS

	2022
ASSETS	
Cash	$ 42,436
Contributions receivable	1,500
Other assets	5,354
Total assets	$ 49,290

LIABILITIES AND NET ASSETS

	2022
LIABILITIES	
Accounts payable	$ 30,640
Accounts payable - related party	1,049
Accrued liabilities	13,819
Total liabilities	45,508
NET ASSETS	
Without donor restrictions	3,782
Total net assets	3,782
Total liabilities and net assets	$ 49,290

The Myalgic Encephalomyelitis Action Network
Statement of Activities and Changes in Net Assets
Year Ended September 30, 2022

REVENUES WITHOUT DONOR RESTRICTIONS	
Grants and contributions	$ 641,269
Gain on Paycheck Protection Program loan forgiveness	70,085
Total revenues	711,354
EXPENSES	
Personnel	463,432
Contract services	104,543
Equipment and digital services	37,404
Facilities and travel	17,799
Office expenses	12,375
Other miscellaneous expenses	17,805
Total expenses	653,358
CHANGE IN NET ASSETS	57,996
NET DEFICIT WITHOUT DONOR RESTRICTIONS, beginning of year	(54,214) $
NET ASSETS WITHOUT DONOR RESTRICTIONS, end of year	3,782

See accompanying notes.

The Myalgic Encephalomyelitis Action Network

Statement of Functional Expenses

Year Ended September 30, 2022

	Program services					Supporting services			
	#MissionsMissing	Digital advocacy and awareness	Research and medical	Other programs	Total program services	Management and general services	Fundraising and marketing	Total supporting services	Total all services
Personnel	$ 85,619	$ 85,979	$ 147,569	$ 14,460	$ 333,627	$ 54,345	$ 75,460	$ 129,805	$ 463,432
Contract services	800	7,980	7,260	-	16,040	87,853	650	$ 88,503	104,543
Equipment and digital services	-	15,797	28	-	15,825	13,130	8,449	21,579	37,404
Facilities and travel	15,963	-	193	-	16,156	505	1,138	1,643	17,799
Office expenses	-	29	51	-	80	11,914	381	12,295	12,375
Other miscellaneous expenses	226	126	-	-	352	16,111	1,342	17,453	17,805
	$ 102,608	$ 109,911	$ 155,101	$ 14,460	$ 382,080	$ 183,858	$ 87,420	$ 271,278	$ 653,358

See accompanying notes.

The Myalgic Encephalomyelitis Action Network
Statement of Cash Flows
Year Ended September 30, 2022

CASH FLOWS FROM OPERATING ACTIVITIES	
Changes in net assets	$ 57,996
Adjustments to reconcile change in net assets to net cash used in operating activities:	
Gain on Paycheck Protection Program loan forgiveness	(70,085)
Changes in assets and liabilities:	
Contributions receivable	(1,500)
Other assets	(1,423)
Accounts payable	26,298
Accrued liabilities	(4,054)
Net cash provided by operating activities	7,232
NET CHANGE IN CASH	7,232
CASH, beginning of year	35,204 $
CASH, end of year	42,436

See accompanying notes. 7

STAFF

Shalida Dobbins | Activist and Volunteer Coordinator

Ben HsuBorger | US Advocacy Director

Laurie Jones | Executive Director

Holly Latham | Social Media Manager

Marynka Marquez | Development Coordinator

Steven Molony | Video and Communications Manager

Erin Roediger | Programs and Campaigns Director

Jaime Seltzer | Scientific Director

Chimére L. Smith | Consultant

Adriane Tillman | Public Relations Manager

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