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Meredith Cowden - AML Survivor, Executive Director at the Meredith Cowden Foundation and GVHD Alliance

Operator: Thank you for standing by. My name is Jordan, and I'll be your conference operator today. At this time, I'd like to welcome everyone to the Lunch & Learn with the LINK.

All lines have been placed on mute to prevent any background noise. After the speaker's remarks, there will be a question-and-answer session. If you'd like to ask a question during this time, simply press star followed by the number one on your telephone keypad. If you'd like to withdraw your question, press star one again. Thank you.

I would now like to turn the call over to Jennifer Gillette. Please go ahead.

Jennifer Gillette: Thank you, Jordan. Yes, I am Jennifer Gillette, the Staff Social Worker at the National Bone Marrow Transplant LINK. I'd like to warmly welcome you to our Lunch &Learn with the LINK program.

Today's program will focus on Bridging Research and Reality with Meredith Cowden: Understanding the Impact of Chronic GVHD on Patients and Caregivers. We'd like to extend a special thanks to our generous sponsors, Blood Cancer United, Incyte, Sanofi, and Mesoblast. We also sincerely thank our esteemed LINK partners for their continued support.

Just a brief outline of our program today. One, we'll have a very brief introduction for those who are not familiar with NBMT LINK. Then we will hear from Meredith Cowden, a longtime survivor, leader, advocate, and counselor living with chronic graft-versus-host disease, who will share her personal journey and insights from a recent study she co-authored with leading GvHD clinicians. The study analyzed more than 12,000 social media posts from patients and caregivers, capturing candid, real-world experiences often missed in clinical research.

Meredith will highlight four key themes that emerged, including the significant physical, mental, and emotional burden of Chronic graft-versus-host disease and its often overlooked impact on caregivers. And then we will have our question-and-answer session and closing remarks.

So, about the LINK for those who may not be familiar. Our mission is dedicated to helping individuals and families navigate the transplant and cellular therapy journey, from diagnosis through survivorship. We do this by providing education, emotional support, and providing trusted resources. Some of the ways we do this is through our content-rich Facebook community featuring daily inspiration, educational updates, and survivor tips. We have our educational books, referrals, and emotional support available. We have our last Wednesday of the month program to connect and support with fellow survivors. This includes our writing workshop, meditation, crafting, and more. We have our arts program and then the Lunch & Learn calls like you're on today, a monthly program featuring healthcare professionals alongside patient and caregiver voices discussing all things transplant. We have our Marrow Masters podcast, which cover, again, all things transplant, including caregiver issues. And we have over 20 seasons, and we have approximately 45,000 downloads right now. So if you haven't checked those out, I highly encourage it. We have a couple of webinars coming up this fall, our Coffee Klatch support group, our peer support programs, our Celebrating Second Birthdays program, and our Survivors Thrive Book Club. So, if you're interested in any of these programs or additional support, please reach out.

Just a couple of housekeeping items. One, as we begin today's program, please, when it comes to our question-and-answer session, please try to be concise with your questions so we can get as many as possible today. And then, while we address many questions, we might not get to all of them. And also remember, anything in this program is meant to stimulate conversation with your healthcare team and does not replace your individualized medical program.

So now on to our speaker, Meredith Cowden. Thank you for being here, Meredith.

Meredith Cowden: Thanks so much. I really appreciate this opportunity. I'm happy to be here. Okay, so I think I'm going to get started.

So I want you all to please just take a minute and just imagine with me, if you will, that it's two o'clock in the morning and somewhere in this country, a person can't sleep because their eyes are so dry that it feels like sand under the lids. Or their skin has pulled so tight across their knuckles that making a fist hurts. They open their phone, and instead of calling anyone, they type. They post. Maybe it's a question to a Facebook group, maybe it's a single line on X that says, “Does anyone else feel like their doctor doesn't believe how bad this is?” They're not writing for a study. They're not writing because it's two in the morning. And they're writing because they need somebody else to understand and to listen to them. And so with this study, what we did is we went looking for people like that, not to interrupt them, not to survey them, just to be the people who listen to them.

And what we found became a study, but it started, and it still starts, with real people describing a disease that doesn't always show up on a lab report: chronic graft-versus-host disease, or chronic GvHD.

As Jen said, my name is Meredith Cowden, and I'm an AML survivor, a patient advocate, and I currently am the Executive Director of the Meredith A. Cowden Foundation and the GvHD Alliance. And so before I go any further into the data, I want to tell you about why this topic isn't abstract to me. As I said, I am an AML survivor. I was diagnosed with AML in May of 2001, many moons ago, when I was 19, and I needed to have a bone marrow transplant. And my older sister was a perfect match. And so I had a very successful transplant in September of 2001. Very shortly after that, I developed acute graft-versus-host disease, which affected my skin and gut before chronic GvHD took hold in 2002, starting with my skin and then touching many organs, including my muscles and joints, eyes, lungs, mouth, and more. I've had more than two decades of treatment, steroids, and several other GvHD medications. And I have to say that the direction of my life path has really been guided by chronic GvHD, such as becoming the patient advocate that I am today. And my day-to-day life is most often structured by my symptoms and how I've learned to live with GvHD. And so this is really the idea behind everything that I'm about to share. With this study, we went looking for the parts of the chronic GvHD experience that are the day-to-day that never make it into that 15-minute clinic visit, and we found them in people's own words on social media. So over the next half hour, I want to walk you through how we did that, what we heard, and what I think it means for how we support patients and caregivers looking forward. And what I'll do is pause along the way, in and out, and share some of my own story and kind of integrate it into the larger experience because data is only half of this conversation. The other half is that lived experience, mine, and I imagine some of yours who are listening in today.

So I want to start by just sort of describing what GvHD actually is and why it's so hard to capture in a normal clinical encounter. Chronic GvHD can happen after an allogeneic stem cell or a bone marrow transplant, which is a transplant using a donor cell rather than your own cells. The donor's immune cells, which are supposed to help fight off disease, sometimes start to recognize the patient's body as foreign and then begin attacking healthy tissue instead. Unlike the acute form of GvHD, which tends to show up early and resolve, chronic GvHD can last for years. For some people, like me, decades, and it doesn't limit itself on organs. It can affect the eyes, skin, mouth, lungs, guts, liver, joints, muscles, and many more. Sometimes several organs at one time, and sometimes in ways that can flare up and then calm down and flare up again without any kind of warning. And this is a number that I believe is worth sitting with. Historically, chronic GvHD has affected roughly a quarter to more than 40% of people who receive an allogeneic transplant. And even with newer approaches like post-transplant cyclophosphamide (PTCy), which has meaningfully reduced the risk, it doesn't eliminate chronic GvHD. And so it's still very much a part of the transplant story for a large number of survivors. The treatment usually starts with steroids, often paired with another immunosuppressive medication. But about half of patients become resistant to steroids or dependent on them long term, neither of which is the place that anybody wants to be.

And so when that happens, there are now, thankfully, FDA-approved second-line options like ruxolitinib and ibrutinib, and then third-line options, belumosudil and axatilimab, which is real progress. But here's the gap that this study was built to address is that none of these drug names tell you what it actually feels like to live with this disease. Clinical trials don't consistently capture patient-reported outcomes. And a clinic visit, by design, is short, structured, and focused on labs and exam findings. And so there usually isn't room in the, like, 15 minutes that you have to talk about how dry eyes have changed your ability to drive at night or how tightness has changed the way you move through your own home. My own organ involvement includes skin, muscle and joint, ocular, pulmonary, oral symptoms, and neurogenital symptoms. And my clinic visits with my hematology oncologist are short. And so there isn't always enough room for us to cover all of that in one sitting. On top of that, like I imagine many of you, I also see several specialists. And each one is focused on the piece of the puzzle that I'm seeing them for. And so that adds another layer of difficulty. And I find that it's hard to communicate everything that's happening in a way that's clear and complete so that my entire treatment team actually understands how chronic GvHD is affecting me in my day-to-day life. So within this study, we kind of thought about it and wanted to ask a different question. Instead of relying only on what the things that are said inside a clinic visit are, we thought about "What if we listened to what people were already saying to each other in public when no one was asking them a structured question at all?" And that's where this method called social media listening comes in. It's been used before in metastatic breast cancer, in advanced bladder cancer, and in chronic GvHD in Europe. But this study that we did was the first one to focus specifically on the U.S. chronic GvHD community, both patients and caregivers, in their own words, over a two-year window.

So how do you actually turn thousands of social media posts into something that you can learn from? So what I'm going to do now is kind of I'm going to walk you through the method. What we did is we used a listening platform called Talkwalker to search across nine kinds of public spaces where people talk. The ones that we took a look at were X, which used to be Twitter, TikTok, Instagram, Reddit, Facebook, YouTube, podcasts, blogs, and online forums. And we limited the search to just the United States and to a two-year window from September 1st, 2022, through September 1st, 2024. And I'm going to ask you to think about what came next, sort of as you would think about a funnel. So at the top, our search terms pulled in 12,476 posts. So basically, anything that mentioned chronic GvHD in that window. That is a huge, messy pile of internet content, and a lot of it wasn't really helpful for us. So then the first thing that we did was we tried to clean it up. We took out posts from news outlets, clinics, and advocacy organizations; accounts that weren't actually patients or caregivers who were speaking for themselves; and we excluded posts using terms like acute GvHD because that's not what we were looking for; we were looking for chronic. And then so what was left was our core analytics set: 5,051 posts from 2,920 unique authors. That's about 40% of what we started with. And these were real people talking about their real experiences with chronic GvHD. And then from that core set of 5,051, we randomly sampled a smaller group: 1,278 posts from 378 unique authors, for a deeper, more careful reading. And we called this the qualitative analysis set.

So why these two tiers, you ask? Because for us, they did two different jobs. The larger core set, that larger number, gives you scale. So it can tell you, for example, what percentage of all of the posts mention a particular organ or a particular drug. And then the smaller qualitative set gave us that depth. It's what actually let us read people's words and follow their stories over time. And identify the themes I'm about to walk you through. So with this analysis, we combined an AI-assisted qualitative research tool with something researchers call a netnography approach, which is really basically just a way of saying that we traced one person's posting history over time. So we were reading a disease journey rather than a single disconnected complaint. And I want to be honest about a limitation here, and there's some other limitations that I'll talk about in a bit. These posts were anonymized, so we couldn't always confirm with certainty whether an anonymous account belonged to a patient or a caregiver. We used context clues, and we excluded posts that seemed to come from friends or extended family who weren't primary caregivers or healthcare professionals. And because everything we used was publicly posted and de-identified information, this study qualified for an ethics exemption because we weren't reading into anybody's private conversations. And I have to say, going back to my own experience, I have myself posted about my experiences and my symptoms on social media. And in all honesty, I've waited to see if others could relate. And when I saw my experience was reflected in other people's posts, to me, it kind of felt like a big sigh of relief, you know? It gave me that sense of, okay, you know, somebody else gets it, you understand. And then within the context of the study, I've also thought about my own post being used for something like this, right? Like, this has given me a sense of empowerment and hope that my voice will matter and can help to make that difference.

So getting back to the study, with that funnel in mind, from 12,000 down to 5,000 down to under 1,300, let's talk about who was actually doing the talking and what themes came up to the top. So in our deep read qualitative set, 71% of posts came directly from patients. 15% came from caregivers of pediatric patients, and only 4% came from caregivers of adult patients. And then we had around 10% left that came from other relatives, friends, and patient advocates. We counted them, but we didn't include them in the somatic analysis because they weren't directly from a patient or caregiver. But I want you to sit with the percentage about caregivers for a second- the asymmetry, right? So caregivers of children posted almost four times as often as caregivers of adults. So why would that be? And it's a question that I'd like to pose openly, and maybe it can be a point of discussion in the Q&A because I genuinely don't think that we know the full answer. Maybe parents of pediatric patients feel a stronger pull to advocate publicly on their child's behalf. Maybe adult patients are simply more likely to speak for themselves since they can. It's something we're thinking about and some further exploration. So in the larger core set, the most common platform that we saw posts on was X at about 39% of posts. That was followed by Reddit at roughly a quarter, and then Instagram in third at about 18%.

And then here we get into these themes. So from the deep qualitative reading, four major themes rose to the surface, and I want to name them now as a roadmap because I'll take each one in turn:

- First, we have the physical, mental, and emotional burden of the disease itself
- Second, we have the treatment experience
- Third, the way that people cope
- Fourth, the caregiver burden

And, for myself, when I think about these themes in my own life, I really don't see them as separate. To me, they're very interdependent, and they each shape each other. For example, “How I'm feeling emotionally is tied to what's happening for me physically. And that physical state can be affected by something like my steroid dose. And then that, in turn, ripples out into other parts of life, right? So when I was younger, and my mom was my caregiver, how did it affect my mom? And then, how does it affect… how I show up in relationships today and relationships in general? And so, there's a lot of connection and overlap, I find.

So let's look at that first: the biggest theme, that first one, the physical, mental, and emotional burden. This theme showed up in 78% of all posts in the qualitative set. Just think about that number, right? Almost 8 out of every 10 people who posted publicly about chronic GvHD were describing some form of burden. Whether it was physical, mental, or emotional, it was a burden. So let's start with the physical burden, which appeared in 50% of posts, half of the posts.

And I want to walk through the most commonly named symptoms because each one represents somebody's actual daily life. Dry eyes, skin rashes, digestive issues, including diarrhea and gut pain, hair loss, muscle stiffness, severe fatigue, respiratory issues, and liver involvement. And I'm sure that you're familiar with some of these, if not all of them, right? And within the posts of all of these, dry eyes and skin rashes were mentioned the most frequently. And then across the entire larger data set, skin was the single most mentioned organ of all. And here's the thing that makes this a systemic disease in the truest sense. Nearly half of all posts that named a specific organ actually named two organs together, and about 8% named three or more. This isn't a disease of one body part. It's a disease that shows up in people's own descriptions as patterns of compounding overlapping complaints. And I'm one of those people who has had this show up in many parts of my body. You know, to my knowledge, I have chronic GvHD and at least six major organs in varying severity. And there might be more that I don't realize, or I attribute the symptoms of them to something else. GvHD has, over time, moved throughout my body from my skin to my eyes, mouth, lungs, and genital system. And for me, the most impactful is in my muscles and joints. I spent more than two decades developing and refining my own system to try to predict, track, manage, and live as well as I can with the fluctuating and unpredictable nature of this disease. And so now, keeping that in mind, let's look at the mental burden, which made up 23% of posts. And then emotional burden at 21%. The single most reported symptom in this entire category was anxiousness at 20% of all the posts.

1 in 5 posts mentioned anxiety, and then second came depression at 16%. And then there was a layer of language that I found interesting that goes beyond individual symptoms and into identity itself. People described a struggle with their sense of self. Feelings of invisibility and being misunderstood showed up in about 1 in 10 posts. People wrote about this loss of identity, a sense of isolation, stigma, guilt, and frustration. This is often the part of the data that lands the hardest, and I really want to give it some room rather than rush past it because I think that it's a part of the clinical measures that are least equipped to capture. It's the part that we can't use a Likert scale or a rating scale to really figure out or identify. And there's a compounding cycle here that I think is the study's central insight, and I want to emphasize that physical symptoms speed mental and emotional burden, and that mental and emotional burden, in turn, makes the physical symptoms harder to bear. About 8% of posts explicitly describe this cycle in their own words without anybody prompting them to.

And this next bit I want to share is something quite sensitive, and so I'll state it. Plainly, and I'm moving forward with intention here, is that within the posts that we reviewed, 15 of them specifically mentioned suicidal ideation. And that number really matters. And I don't want to move past it too quickly. And as a therapist, they will say, if this topic brings anything up for you today, or if you or somebody that you love is struggling, please know there is support available right now in the United States. There's a number, 988, that you can call or text anytime; they are like... so please keep that in mind if you or someone you know is struggling. Within the data, some patients did describe going to psychiatrists or GvHD-specific therapists or support, and 11 posts specifically mentioned that antidepressants helped with feelings of hopelessness. And so, I find that these posts remind us that when people find the right support, it can genuinely help. I want to close this theme on the one clearly positive finding so that we don't end purely on pain. In about 11% of posts, patients described their relationship with their healthcare provider, specifically their provider's expertise and compassion, as something that genuinely helped them. That relationship is a really good bridge into what happens once someone is actually in treatment. And so I want to move into that next, so what patients and caregivers told us about the treatment experience itself.

So we have 42% of posts in the qualitative set and 24% of the larger core set mentioned a specific kind of treatment. The two most frequently mentioned treatments overall were tacrolimus and ruxolitinib. And I know that there are various different ways to say these drugs, and that's how I'm saying them. I hope they're right. And in the larger core set, steroids were the single most discussed treatment of all, which makes sense, given how they're often the first line of defense and, for many people, like myself, a long-term companion. Some other treatments that came up included belumosudil, extracorporeal photopheresis (ECP), axatilimab, and ibrutinib. And here is a pattern that held true almost no matter what specific drug people were talking about. The pattern was variable efficacy, fluctuating effectiveness, side effects, time burden, and cost. These four frustrations showed up again and again regardless of what the medication was actually being discussed. So it didn't matter what they were taking. Variable efficacy in the drug, side effects, the time burden, and the cost kept coming up in these posts. Access and cost deserve their own moment. About 10% of posts described real difficulty gaining access to newer treatments.

About 8% specifically flagged the financial burden of care. And those are two distinct problems. One is about whether a treatment is reachable at all. And then the other one is about whether a patient can actually afford it once they can get to it or once it's available to them. And one I found emotional finding that surprised myself, well, not really myself, I guess I shouldn't say that - but some of the others in the research team. Trauma was the single most commonly mentioned emotional descriptor tied to a specific treatment. So trauma, that statement, was more common than fear, more common than frustration. And I think that's worth a minute, right? It tells that for many patients, it isn't only the disease; it isn't just chronic GvHD that feels traumatic; the treatments, the process of trying to get better, can carry its own weight as well. You know, in my experience, I haven't been able to stop taking steroids since I developed acute GvHD in 2001. That's 25 years of my life on various doses ranging from 7 mg, which is the lowest that I've successfully gotten to, up to 80 mg, if my memory serves me correctly. And today, I'm still taking the steroids plus other forms of treatment along with the medication that I need to manage the side effects and the long-term effects of the treatment itself. And because of that, for me, treatment can feel like a contradiction. Sometimes to me it's just another symptom almost to navigate. And sometimes it's the magical relief that I've been waiting for.

On side effects specifically, general safety impact was described in 27% of qualitative posts. And people named osteoporosis, nausea and vomiting, diarrhea, mouth sores, joint damage, changes in appearance, and changes in mood or personality. And this is another area where I want to be honest about a limitation: because of how this data was coded, we can't reliably attribute a specific side effect to a specific drug. We can only say that the side effects broadly showed up often and mattered a great deal to the people who were describing them. So, given everything that we've just covered, the burden, the treatment struggles, the natural next question that we came up with, that we saw, is how people were actually coping. And this is a smaller theme by volume, about 13% of qualitative posts, but it's quite rich in practical, usable detail. And there were two very interesting ways of coping that came out of this. The most consistent coping strategy was peer support. Patients and caregivers described connecting through online communities and support groups as a primary way of getting through difficult stretches, and it wasn't instead of medical care but alongside it. Roughly 5% of posts discussed navigating the healthcare system itself. So, looking at disability applications, long-term unemployment, government insurance programs, and financial assistance. So, in these posts, people are essentially teaching each other how to navigate bureaucracy that no one had prepared them for. And then the second theme I find especially telling is that a coping strategy in its own right was specialist speaking. People identified dermatologists, gastroenterologists, endocrinologists, ophthalmologists, and GvHD specialists. And so they were actively assembling their own multidisciplinary care team one referral at a time because the system hadn't handed them one already. Only two posts out of the entire qualitative set mentioned an actual multidisciplinary chronic GvHD clinic. That gap between what patients are clearly seeking and what's actually available to them is one of the most important findings in this study.

And in my experience, like I mentioned earlier, and it's very similar to what's happening that's seen in the studies, I have a team of several specialists, and it's a group of tremendous people who I found either through referrals from one another or through my own research into who could give me the care that I believe I need. And over the past couple of decades, I myself have essentially constructed my own version of a GvHD clinic. And in my experience, that effort reaches beyond my direct care team too. So what I've done is I've often reached out to a provider I know or know of just to ask a question. I've found that there's really no harm in seeking information as long as I know how to put what I learned to meaningful use. And when I think about a GvHD clinic, I can only imagine what that would be like, right? Something that's already built and ready, and the profound impact that could have on the overall burden of living with chronic GvHD. I mean, I truly believe that it could be of tremendous value to all of us.

And then there is one more theme, and I think that it's the one that gets the least attention in the clinical setting, and that is of the people who are doing the caregiving. So this theme was the smallest by post volume. Only 4% of posts were explicitly framed around caregiver burden. But I want to say clearly, this theme had to be analyzed manually by hand because there weren't enough posts for the automated tool to detect a reliable pattern. And that smallness in itself is a finding. Caregivers, it turns out, don't talk about their own burden very much, even when they are clearly carrying a great deal of it. Within this smaller set, a few distinct patterns emerged. Adult children caring for a parent often described suppressing their own emotions, specifically to avoid burdening that parent further, which over time led to real internalized stress. Then young adults in their 20s and 30s described balancing caregiving with their own social and professional lives, household tasks, emotional support, and medical logistics layered on top of their already demanding life stage. And then spouses and partners who served as primary caregivers described managing medical care and advocating for their partner. And notably, they also described how the disease affected physical intimacy and the broader dynamics of their relationship. And then, looking at parents of pediatric patients. They described a different flavor of burden altogether, which was this very heavy investment in research, advocacy, and seeking out expert opinions for their child, and all while trying to hold together work and household responsibilities.

For me, when I was 19, I was diagnosed with cancer, and I was very young when I started my chronic GvHD experience, so my mom was my primary caregiver during that early part. And she kind of fit into that parent of a pediatric patient, research-oriented advocate because I, as a 19-year-old, couldn't fully be that for myself. And I believe that being a caregiver took on a very defining shape in her life, and it's certainly a part of who she is today. And I have an immeasurable amount of gratitude for her and the wonderful ways in which she cared for me. And I have to say that our relationship today has really been shaped by that caregiver-patient dynamic, and it's brought us close in a way that I don't think would have happened otherwise. And with that in mind, and the impactfulness of the lack of data and the small data that we found, you know, caregivers are so much more than what that word caregiver might suggest. And I think that's something that healthcare professionals and support organizations and we all kind of need to keep in mind.

So what does this all add up to as a whole? So I'm going to close with what I think this study means and where it honestly falls short. I think that this study is genuinely good for surfacing real, unfiltered, first-person language that a clinical checklist simply is not built to capture: the invisible symptoms and the identity-level impact of living with a disease that can last decades.

I also want to name its limitations, honestly. I'll keep it to three. So first, we have selection bias. This one reflects people who were using… It only reflects with people who were using public social media in the United States during a specific two-year window. That likely skews toward visible, describable symptoms like skin and eyes and away from things people might be too sick to post about, like pulmonary GvHD, or things people may simply choose not to post about due to stigma or privacy, like urogenital symptoms, which didn't appear in this data set at all. Secondly, we can't always attribute a specific side effect to a specific drug, as I mentioned earlier, and we can't always confirm that one anonymous poster represents one actual person. Thirdly, this study only captured public posts. And I think that to me feels like a very large limitation because I know, and I'm a part of private groups, like there are several GvHD groups that are private that are on Facebook that are huge. And so, these groups almost certainly hold additional different conversations that we just simply couldn't see. With all of that being said, none of it undercuts the value of what we found. Even a partial, imperfect window into unfiltered patient voice adds something that clinical encounters and structured outcome measures on their own just don't.

And so in closing, I want to go back to where we started, imagining that person at two in the morning, right, describing symptoms that nobody else seems to be asking about: what changes if we treat that post, that moment, as data instead of noise? I think that with that in mind, a few things change: conversations between patients and their health care providers can become better informed. Supportive care research can become more targeted, aimed at the burdens people are actually describing, not just the ones that are the easiest to measure. And I think there's a real case. This study makes it directly for those multidisciplinary chronic GvHD clinics because patients are already trying to build that kind of coordinated care for themselves and are putting in the mental, emotional, and logistical work to do that. And that adds significant burden. And so having it already in place lifts a lot of that weight. And so, looking ahead, I think that future work should pair this kind of listening, social media listening, with direct qualitative interviews. And it should expand the search terms used, with this study specifically; it flagged missing language around things like shortness of breath. We didn't find bronchiolitis obliterans, vaginal dryness, and urinary issues; gaps like that reflect stigma and privacy, not a lack of real impact. So it's not like they're not happening. It's just that we need to look for it. We need to listen for it.

What stands out to me, both in my personal experience and in what we found here, is that chronic GvHD, as a systemic disease, needs an equally systemic approach. Not just to treating it, but to living with it. I find that it's far more complex than what can be addressed in a clinic setting or captured through survey questions.

I find that for myself and others that I've had the opportunity and privilege to speak with and learn from, it profoundly shapes the lives of those that it touches. And my hope is that this study can take us one step closer to building the ecosystem of care and support that's truly needed, and one that can make a real impact for people seeking that connection and understanding, whether it's 2 a.m. in the morning, 2 a.m., or 4 p.m. in the afternoon or evening. This is something that we are moving forward in terms of figuring out how to look at it in that larger structure. And I think this is taking us one step closer and helping people.

And so, I just want to close. I think I said that this is the third time I said that now, but this is for real. Thank you. This study was funded by Sanofi, and I would like to very sincerely thank my co-authors, Shernan Holtan, Claudine Derrien-Connors, Kathy Marshall, Ron Preblick, and Miguel Perales. And I thank you so much for listening to the data and to the people behind it. I want to thank those people too. They might not know that their voice is part of this, and I'd be happy to open it up for questions or discussion. Thank you so much.

Jennifer Gillette: Thank you so much, Meredith. And Jordan, can you please tell everyone how they can ask a question?

Operator: I certainly can. If you'd like to ask a question, simply press star followed by the number one on your telephone keypad.

Jennifer Gillette: And while we wait for people to line up in the queue, I have a question for you, Meredith. When you talk about constructing your own GvHD team, how did you… I know you said you did your research, but do you have any recommendations for people that maybe just feel like they're not really getting what they need, and how they can try to find some of those qualified people to really try to help them?

Meredith Cowden: Yes. Definitely. I think that… So I found some of it was very kind of serendipitous, and it's one of those things in life where it's like, okay, this person knows this person who knows this person. So there was that sort of natural connection piece, but then and other ways of figuring out and finding providers. I know that another wonderful patient advocacy organization, BMT InfoNet, has a provider directory. And I know that they are currently working to expand the GvHD specialists and the GvHD practitioners who are in the community and not just in the larger institutes or at transplant centers. And so that people can go on there and do some research. And the other thing too that I found is, it's you make a couple phone calls, and I kind of think of it, there is a bit of work to it is, I kind of think of it like interviewing people, right? Like you might meet with somebody and it feels like that person has the kind of knowledge and the kind of ability and information and skill set that you need. And then, it might turn out that maybe they don't, and so then talk to somebody else. Oftentimes, I found that my providers work well with each other, so they kind of have their own networks that they work within, and so that in and of itself has been helpful. And also sometimes those people are not the people that work for me, and so then I'll go on BMT InfoNet's site.

Or the other thing that I like to do, and then I'll stop talking about this, is I like to… like for instance, like the stuff like Lunch & Learns or like the podcasts that you guys have, I'll look and see who the doctors are and then I'll look them up and then I'll see if there's a way that I can get in touch with them, even just for like a consultation. And then that's information that I can pass on to my providers specifically or ask them to connect with each other because there's no harm in creating that connection and that communication. Did I answer that other question, Jen?

Jennifer Gillette: You sure did. Thank you for that lead there. That was perfect. Thank you. Jordan, is there anyone on the line yet?

Operator: There is. Your first question comes from the line of Elise Fine. Your line is live.

Elise Fine: Thank you. Thank you very much. Melissa, your presentation was flawless, absolutely excellent. You've definitely walked in the shoes of the fitment. I am the caregiver, and I am in shock that no caregivers have participated in what you tried to do. If I'm not being too personal, how old are you now?

Meredith Cowden: Now I'm 44. I'll be 45 in October.

Elise Fine: Okay, so you're out quite a way. My husband is 16 and a half years out. In June, he just celebrated his 80th birthday, which is blowing my mind.

Meredith Cowden: Oh, happy birthday.

Elise Fine: Thank you. But I am finding that he is having very poor care, and I believe it's senior abuse, for lack of a better word. He was in the hospital back in June of 2025, and I actually filed the police report because he was so bruised from blood draws that it was just incredible. He had the chronic GvHD of the eyes and the musculoskeletal system, and he's in terrible agony. We see the ophthalmologist monthly. He had to have a cornea transplant, and then the original cornea- the new cornea method was failing, so they had to do it with the Tarsorrhaphy. They sewed his eye halfway closed so that he even has left vision. And that was the most frightening thing on the consent form for BMT, more so than even death, was the word blindness. He actually told the doctor, if I can go blind, I don't want to go through the transplant. And as a caregiver, I can honestly and truthfully tell you that, watching him for the last 16 and a half years, if this was ever me, I would never go for a bone marrow transplant, watching the chronic graft-versus-host disease. It has been harder than the diagnosis and transplant itself. So he has to see an ophthalmologist monthly, where he wears bandage contact lenses. Doesn't do anything to help his vision; it just protects the cornea. And he has extremely bad musculoskeletal pain. And no matter what I bring up, I know you mentioned some of the drugs; he was on some of the prednisone for a while, but that gave him avascular necrosis, so we're not doing that now anymore.

No matter what I suggest to the doctors or anything like that, they tell me no; he's just under sirolimus, and actually that's been reduced over the last few months. And the doctor that he has was the transplant doctor up at Moffitt Cancer Center in Tampa, Florida. And up there, I saw he walked on water, and he was transferred down here to South Florida to open a Moffitt satellite office at Memorial Cancer Institute. And he's not the same person. And now I really can't stand him. He's just totally different.

What do you recommend trying to get the doctors to understand? We had been to a psychologist who told us he ran out of words. We've been to an interventional doctor who told my husband in closing the report, he said, see your OBGYN. The care has been abominable, and I don't know what to do or how to handle it anymore. And it's taking its toll on me. I can tell you that I'm 77.

Meredith Cowden: I mean, it sounds like both of you have had quite an experience with this, and I'm sorry to hear that. And so, I think that one of the things that I found that helps to facilitate or to get a better understanding or a clearer picture across is I kind of think about it in terms of communicating around a goal. And I'll say, like to my hematology oncologist or my rheumatologist, I want to be able to walk down the street without running out of breath or having immense pain or whatever the thing might be. And I want to do this by this point. What do you need to know to get me to that place? And put it in these very specific terms like that so that there's that bridge from the symptom to the life experience. And so, sitting down and talking with your husband about whatever that might look like and then communicating that to your doctor. I will say to the other thing is that if you feel like he's not getting the kind of care that he needs, you know, that's a conversation to have with somebody on the treatment team; it doesn't have to be the doctor, it can be the nurse, it can be a different provider. It's something to certainly share because they need that feedback.

Elise Fine: I have wanted to switch providers, but they won't let me. I wanted to change providers within the cancer center, but they won't let me because the doctor that we're using was his transplant doctor, and we're being told he's the correct doctor. And whenever I've done what you suggested because I thought it was the correct route to take, what points and all, he would say is you have sciatica, spinal stenosis, and herniated discs. Nothing can be done for it. You know, you have to live with it. When we saw him last, my husband's been getting terrible, terrible chills. And we're living in Florida. It's a 112 heat index down here. He's shaking like a Parkinson's person. I've never seen anything like that. He's sleeping with four blankets. And I mentioned it to the doctor during the course of the visit back in July. And he said he wasn't familiar with it. He was going to do research. He never got back to me. I sent him two emails. Yesterday I spoke to the nurse practitioner. I get nowhere with anyone, and that's what's very frustrating. So is there any way of contacting you?

Jennifer Gillette: Elise, if you want offline, you and I could maybe talk, and maybe I could try to see if there's any other people in your area that we could reach out to. I want to make sure that if we have other people on the line, we can try to answer their questions too, but I'm happy to help you offline with that.

Elise Fine: Is there any way of reaching out to Melissa privately?

Meredith Cowden: Yes, I can. Yeah, go ahead, Jen.

Elise Fine: All right. So, Jennifer, when I talk to you, you'll tell me how to reach out to her then, I guess.

Jennifer Gillette: Okay. I will reach out to her and ask her what the best way to do that. But thank you, Meredith, for answering that. And I'm so sorry, Elise, for what you and your husband are going through, but I'll reach out to you after this call. Jordan, do we have other people on the line?

Operator: Your next question comes from the line of Kathy Spence. Your line is live.

Kathy Spence: Hi there to all of you, and thanks so much, Meredith, for all the work that you do not only on this paper but everything else that you do. And I'm sorry I missed the first half hour. Unfortunately, I had a typical thing about the life of a GvHD patient. I am 10 years out from BMT, and I had an appointment before this, so I missed the first half hour, unfortunately. Because even 10 years out, I still have so many appointments, and it does feel like quite a burden. I have GvHD basically from head to toe, and despite 10 years past, but sort of managing okay; I've got post and a few other big problems. But one of the questions I have, Meredith, is that we talk about caregivers all the time, and do we actually have a definition of a caregiver? Because one thing I'm thinking is that some people, such as myself, don't really have what you would consider a traditional caregiver, as in somebody who would make your appointments, encourage you with your meds, that kind of thing. So I'm thinking that we have a population of patient with GvHD or post-bone marrow transplant. Would the numbers also be a little bit deviated because we don't have a definition of caregiver and therefore of caregiver burden, since some people don't really have a caregiver by what I would consider the traditional sense?

Meredith Cowden: I think, Kathy, you bring up such an amazing point. And I think it's something that I'm super interested in, because I think you're absolutely right that there are so many people who don't have that, like, traditional idea or like role person of a caregiver who's there helping make the appointments and doing all of these things. And so, it's sort of a community. And I think then we need to really kind of think about going back to what I was saying around sort of building out an ecosystem is really think about how to expand the definition of what caregiving actually means. And it's a really interesting exploration to do something similar with the social media listening and getting information from people about what caregiving looks like for them and what it looks like for you, like what that means for you. And then using that to better understand, how does a variable, different way of caregiving impacts you and the people within your community. I really appreciate that. You know, I think that's important, and I think we do need to explore that definition and what it's like, the meaning, the true meaning of what it is for people in their lived experiences.

Kathy Spence: Yes. No, I agree and I'm just wondering how we could do that.

Meredith Cowden: Well, I think that I think more… You know, I really enjoyed doing this, this kind of study. And so I think doing more like this. And I think kind of figuring out ways of expanding this kind of study to reach some of the voices that we couldn't necessarily access. And maybe having something that, when we look at the language that we're searching for, thinking about taking potentially like a group of patients and people and caregivers and talking to them about some of the somatic words or some of those things that might come up, and then using that information to kind of do that larger exploration and then the more specific explorations. And I think too, the other thing, like there's so many things, we could also do like a… we could look at in terms of like a… I really love the patient advisory board kind of stuff, or like a workshop or a focus group and just getting a real clear understanding and looking at it from that qualitative perspective rather than the number-oriented or scale-driven clinical information.

Kathy Spence: You know, in September 2027, there's going to be the international GvHD combining with the Meredith Cowden. And we're wondering whether this might be something to look at there, like the definition of a caregiver, the role of a caregiver, in patients without caregivers. Because not only do some people not have caregivers by choice, perhaps, or caregivers by lack of caregiver interest, but also they might not have a caregiver in their circle of family or friends to be available more than as well. How do we try to make up for that loss? So just a thought.

Meredith Cowden: Yes. I think, Kathy, let's connect after this, and I think that's a great idea. Let's talk about it for sure.

Kathy Spence: Yes. And just by any chance, are you involved in a meeting… sorry, to everybody else… For this 3:30 on the 26th planning meeting, are you involved in that one at all? For the 27 you are?

Meredith Cowden: Yes.

Kathy Spence: Okay. I'll be there.

Jennifer Gillette: Thank you, Kathy. We can take one more question, Jordan, if there is one.

Operator: The final question comes from the line of Steve Hodges. Your line is now live.

Steve Hodges: Thank you. Meredith, terrific. Thank you for your advocacy and research. My question is, if we imagined an organization that would do what you suggest, which is to connect all these capabilities, and instead of lists of providers that patients or caregivers have to shop, they would be connected to the right places, what would that capability look like?

Meredith Cowden: It broke up for me just a little bit. Can you say that again one more time?

Steve Hodges: Yes, I'm sorry. If we imagine an organization that connected the capabilities that we're talking about, and so instead of a shopping list of providers and contact numbers for patient triggers, they would be warm connected to the right capabilities, what would that function look like if it provided?

Meredith Cowden: I mean, I think that that's a wonderful question, Steve. I think that I'm not sure yet. I think that that's something that we need to explore and think about some more, and I like that idea, right? Rather than creating this sort of, like, laundry list of options for people, having something that's more what sounds to me like tailored in a way is what I think you're saying. And so, I think that's a great area that I want to think about some more and figure out a way to imagine what that could look like because I think that would be one of these great solutions for people. Thank you.

Operator: That concludes the question-and-answer session. I'd now like to turn it over to Jennifer Gillette for closing remarks.

Jennifer Gillette: Thank you so much, Jordan. First of all, I want to thank Meredith. What an amazing study, and we appreciate you sharing your findings and sharing your experiences, as well as everything that you and your family do for the GvHD community. You and your family are certainly a treasure to all of us. But I have one more question for you myself as we are getting ready to close, and that is… I saw some questions from our providers of coping through this long, hard disease. And I know everybody might have different journeys that might look different. Some people might have milder forms. Some people might have more severe forms. What are some of the things you do in these 25 years of coping with this that help you to get through the tougher times with it?

Meredith Cowden: I found that… well, first of all, thank you, Jen. I really appreciate the kind words about the work I've done in my family, and I thank you so much. I found that, for myself, just from a sort of emotional and psychological standpoint, when there are these fluctuations and the ups and downs and the roller coaster of medication and symptoms, I try very hard myself to zoom out of the situation that I'm in, and so I pull myself out of the weeds. And I think about the situation from the broader lens. And so this is a moment in time. This is not all of time. And then I like to figure out a way and kind of sit with what's happening so that I reach a state of acceptance around what's currently happening, knowing that it's not permanent. And then I work to adapt as much as I can in terms of what my day-to-day looks like. And so everything that I've done myself, whether it's in terms of my day-to-day way of living or how I look at the treatment team that I'm working with or how it affects my life, is that I see where I can have some flexibility and where I can't. And then I try to work within that space to adapt to what's going on in this moment. And then I kind of use that as a stepping-off point to take the next step towards, what kind of what I was talking about earlier with around that goal, like, what's that next thing that I need in my life to live well? And what's that thing that matters to me the most? And how can I get there with what I have now? And I also find I just really like talking to people. And so, I'll just talk to whomever. And oftentimes, that's how we learn the best is from just talking to each other.

And then we can get hope, or we can get tips, or we can get support. And so that's kind of, I think, the main thing that's really helped me over these past couple of decades.

Jennifer Gillette: Well, thank you for sharing that. I certainly appreciate you doing that. And I have to say, your tips over the years- there was one of our programs you had shared, like even when you were doing your breathing treatments, that you used it as meditation time. And like the breathing in and the breathing out. And I think these things are just so- they're great tips to just help people with the day-to-day, like, how do you figure it out. Moment at a time. So thank you so much. I really appreciate it.

And again, I just want to thank Meredith. I want to thank our sponsors, our partners, and all of you for joining us today. We hope today's discussion provided some useful insight to you or some tips. And as a reminder, if anyone needs additional resources, please reach out to us. We're happy to be here for you, and we thank you for being a part of our community. We hope everyone has a wonderful afternoon. Thank you.

Operator: This concludes today's meeting. You may now disconnect.