

# Global Healthy Living Foundation COVID-19 Patient Impact & Insights



- Patient Support Program Updates
- Education and Support Across GHLF.org + CreakyJoints
- Social Media Outreach
- Patient Council Insights
- Autoimmune COVID-19 Study Updates
- Spanish Language Update
- Advocacy Policy Updates

**July 18 – August 17**

July 18 – August 17, 2020



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## GHLF COVID-19 Patient Support Program for Chronic Illness Patients

In mid-March, GHLF launched a patient support program for people living with chronic illness to help them navigate the coronavirus pandemic— **whether they have COVID-19 or not.**

Informed by our COVID-19 Patient Leadership Council, the program is growing rapidly and meeting the many underserved needs of high-risk and chronic illness patients.

**Go to [www.GHLF.org](http://www.GHLF.org) to learn more**



**17,121**

Number of members

**28,191**

Number of subscribers

**27.4%**

Email open rate  
(health industry average = 22%\*)

**7.7%**

Email click rate  
(health industry average = 2.5%\*)

### Top Conditions:



**30%**

Rheumatoid Arthritis



**20%**

Lung Disease



**13%**

Psoriatic Arthritis  
+ Psoriasis



**11%**

Fibromyalgia



**11%**

Heart Disease



**10%**

Migraine



**9%**

Diabetes



**7%**

Inflammatory Bowel  
Disease

\*Source: Mailchimp Email Marketing Benchmarks



## Patient Support Program Community Poll: Telehealth

72% of participants have had a telehealth (video or audio call) visit with a health care provider in the prior three months and 28% have not



## Patient Support Program Community Poll: Telehealth

**Of the 28% who did not have a telehealth visit, participants had the following reasons for not having a visit** (responses are not mutually exclusive):

- **34%** have not needed to make an appointment with their provider
- **32%** have had an in-person appointment with their provider
- **14%** are waiting until they can have an in-person appointment with their provider
- **9%** do not have the technology needed for a telehealth visit
- **9%** have providers who are not offering telehealth visits
- **7%** do not feel comfortable using the technology needed for a telehealth visit



## Patient Support Program Community Poll: Telehealth

**Of the 72% who had a telehealth visit, participants met with these healthcare provider specialties (responses are not mutually exclusive):**

- **59%** Rheumatology
- **48%** Primary Care
- **14%** Clinical psychology / psychiatry / mental health counselor
- **10%** Pain Specialist
- **8%** Neurology
- **7%** Pulmonology
- **6%** Endocrinology
- **6%** Gastroenterology
- **4%** Dermatology
- **4%** Cardiology
- **4%** Allied health professional
- **1%** Naturopathic or homeopathic



## Patient Support Program Community Poll: Telehealth

**Of the 72% who had a telehealth visit, participants had the following reasons for the visit** (responses are not mutually exclusive):

- **68%** Routine or regular visit
- **39%** Follow-up appointment
- **25%** Visit to address a flare or recent problem with your condition
- **25%** Visit to review results of lab work or other tests
- **18%** Visit to discuss a change in medication for your condition
- **8%** Visit to discuss concerns about coronavirus (COVID-19)
- **6%** Visit to address side effects from one of your medications

**Participants who had a telehealth appointment rated their visit, on a scale of 0 (worst visit) to 10 (best visit), as an 8, on average.**

## Telehealth: What Our Members Are Saying

“

*When the pandemic is all over, I'd like to continue, but maybe alternate or do 1 in person and 2 telehealth, depending on how often I see the doctor.*

“

*I am extremely grateful for the temporary option of telehealth and I really, really want it to become a permanent option. I know that some visits must be in person, but really not many of them have to be and these telehealth visits all took care of my issues just fine in much less time.*

“

*So much easier than driving the 3 hours it usually takes to get to my doctor. And I feel so much safer.*

“

*It was so easy! No driving, no parking, very little wait, and our conversation seemed just like if I were in her office. I see no drawback for this type of visit. I hope I can continue doing some visits this way when the virus calms down.*

“

*The only issue I have is that every provider seems to use a different app to schedule these visits so you have to learn multiple applications. Some applications work better and easier than others so it can be cumbersome. I can do it but older people or people without computer experience may have trouble.*

“

*I was able to ask questions to address my concerns about my health and the risks of COVID. It was very reassuring.*

## Patient Support Program Community Poll: Coronavirus and the Upcoming School Year

*We are surveying our Patient Support Program members regularly about important issues in health care and other topics.*

**18% of respondents reported working in a school (public or private; primary, high school, or college/university; pre-school or daycare)**

**30% of respondents are the parent or guardian of a school-age child or children**

- **14%** have children of preschool or daycare age
- **35%** have children of elementary school age
- **29%** have children of college age
- **24%** have children of middle school age
- **40%** have children of high school age

**All respondents were asked their preferences for the upcoming start of the school year:**

- **43%** wanted completely online schooling
- **35%** wanted a combination of virtual and in-person schooling
- **7%** wanted completely in-person schooling
- **7%** wanted 'Other'
- **6%** wanted homeschooling (through a private or public program)
- **1%** wanted in-person schooling that is outdoors

## Coronavirus and the Upcoming Year: What Our Members Are Saying

“

*I know people use school as a babysitter for their children and not having school open presents a financial hardship for people.*

“

*I would prefer the schools not open until we've reduced the spread of the virus; however, we have a large population of school children who don't have the means for online education. Therefore, in-person instruction would be best for them, preferably outside in the shade.*

“

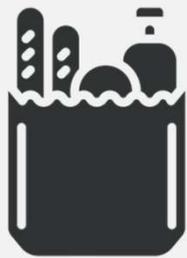
*Having been an elementary school teacher, I can imagine how incredibly difficult it must be to teach on-line. That being said, I also know how impossible it is to get children to follow classroom or school rules in normal circumstances. In this case, it could be the difference between life and death. As a person with chronic health issues, I would feel even more vulnerable to COVID-19 because I can't imagine that won't spread at an even more rapid rate.*

“

*I don't feel it is safe for kids to return. It is too contagious and not being taken seriously by many. This puts everyone at a higher risk.*

“

*My husband is a high school teacher in a private school who plans to re-open. He is 68 with diabetes and I'm 73 with RA & diabetes. He's very concerned but is afraid of losing his job if he refuses to teach in person. He's afraid of exposing himself and passing on to me.*

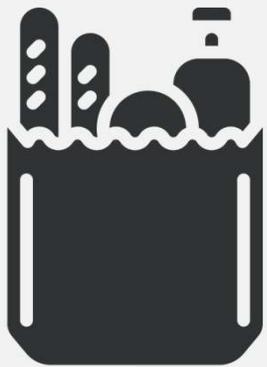


## Patient Support Program Community Poll: Diet & Exercise

We are surveying our Patient Support Program members regularly about important issues in health care and other topics.

# Patient Support Program Community Poll: Diet & Exercise

**How would you say your diet (what you typically eat daily) has changed since the beginning of the coronavirus (COVID-19) pandemic in late-February/early-March?**



- **38%** reported their diet has stayed the same
- **33%** reported their diet has improved
- **28%** reported their diet has worsened

**How would you say your everyday level of physical activity has changed since the beginning of the coronavirus (COVID-19) pandemic in late-February/early-March?**

- **52%** reported they are less physically active now
- **24%** reported their levels of physical activity have stayed the same
- **24%** reported they are more physically active now

# Patient Support Program Community Poll: Diet & Exercise



**How would you say your weight has changed since the beginning of the coronavirus (COVID-19) pandemic in late-February/early-March, for reasons related to diet and physical activity?**

- **34%** reported their weight has stayed the same
- **30%** reported they have gained 5-10 pounds
- **10%** reported they have gained more than 10 pounds
- **18%** reported they have lost 5-10 pounds
- **8%** reported they have lost more than 10 pounds

## Diet & Exercise: What Our Members Are Saying

“

*I was participating in Aqua aerobics at a local pool. It was closed for a while but is now open. I am hesitant to go back but really need that exercise.*

“

*I've been doing some exercise classes via Zoom or following some exercise videos on YouTube. It's not the same as being in a physical group though and I've struggled to stay motivated to exercise.*

“

*I do more planned, concerted exercise, but less casual movement like going on errands, standing in church, walking through parking lots, etc.*

“

*We have been very creative with our food recipes and trying different ingredients. Very successful. Plus going back to our childhood recipes our parents made for us. Yummy!!*

“

*I have spent a lot more time walking and listening to audiobooks. I have been baking more, but have never really eaten out often, so no change there. I've gained about 10 pounds even with the increased exercise and walking but am on steroids and may account for some of the weight gain from that.*

“

*Grew a garden at our farm and that has kept me busy!*

## Patient Leadership Council Insights: On Our Minds

We spoke with our Patient Leadership Council and discussed the concerns and issues they are seeing in their respective disease communities:

### If you had to guess, what percent of people are wearing masks where you live?

- *"Long Island, NY: 90% (living in NY I think everyone here has learned the hard way)"*
- *"Vancouver BC, Canada: 60% (about 40% seem to not)"*
- *"Sacramento, CA 80-85% (but I don't get out much)"*
- *"Baltimore, MD: 80%"*
- *"Jackson, TN: 60% (mandatory mask rule indoors in place - so inside is 60%)"*
- *"Michigan: 60%"*
- *"Arlington, TX: 30%, Fort Worth, TX: 60/70%, Dallas, TX: 40%"*

### Is there an app you use to track your symptoms?

- *"I use OPERAS from Arthritis Research Canada with my Fitbit."*
- *"I use Pain Scale app."*
- *"I used to use Migraine Buddy, but it is more of a calendar"*
- *"I use ArthritisPower, but extremely rarely. If I'm symptomatic for COVID, I just take notes on my phone."*
- *"I use an old-fashioned journal."*

## Patient Leadership Council Insights: On Our Minds

We spoke with our Patient Leadership Council and discussed the concerns and issues they are seeing in their respective disease communities:

### How do you support your overall wellbeing?

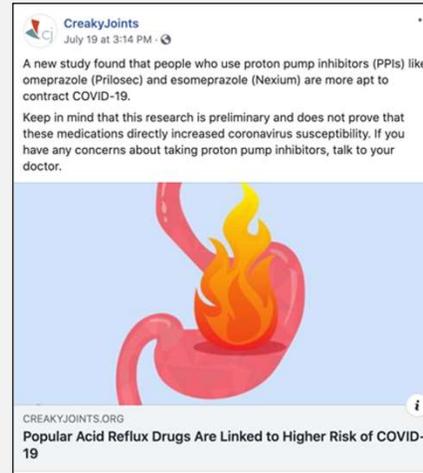
- *"Quarantine pounds are real. Bike rides ankle feet a break, going to the gym, 10 ppl allowed in at a time."*
- *"I have gained for sure, but I've also improved and learn to cook."*
- *"Recently back to exercising regularly and it's made a huge difference; my joints need it."*
- *"My health is "stable" except for some scares with COVID symptoms. Being home is great for me, but I've lost independence in terms of being able to shop for groceries at my usual discount store."*

### Do you use anything other than Zoom to connect with others online?

- *"Uber conference is a good alternative for Zoom if you need to share screens."*
- *"Facebook has been a huge one for me. since chronic migraine forces me to seek a quiet place. I have a community of friends I like to entertain with funny memes."*

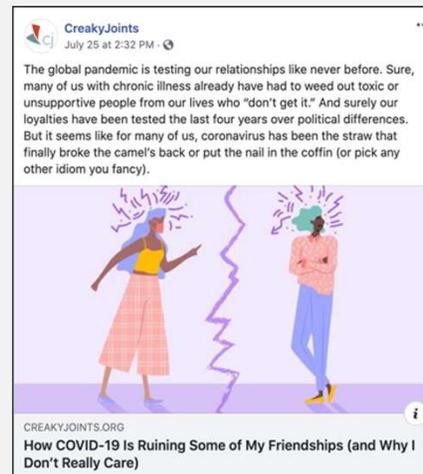
## Social Media Outreach: Top COVID-19 Twitter Content

COVID19 social media that resonated with our community was centered around the emotional impacts of living with a chronic disease during the pandemic. Additional content about medications that could impact COVID19 risk also generated organic discussion and sharing.



A new study found that people who use proton pump inhibitors (PPIs) like omeprazole (Prilosec) and esomeprazole (Nexium) are more apt to contract COVID-19.

Keep in mind that this research is preliminary and does not prove that these medications directly increased coronavirus susceptibility. If you have any concerns about taking proton pump inhibitors, talk to your doctor.



The global pandemic is testing our relationships like never before. Sure, many of us with chronic illness already have had to weed out toxic or unsupportive people from our lives who “don’t get it.” And surely our loyalties have been tested the last four years over political differences. But it seems like for many of us, coronavirus has been the straw that finally broke the camel’s back or put the nail in the coffin (or pick any other idiom you fancy).

## Social Media Outreach: Top COVID-19 Twitter Content

COVID19 social media that resonated with our community was centered around the emotional impacts of living with a chronic disease during the pandemic. Additional content about medications that could impact COVID19 risk also generated organic discussion and sharing.



Living through a pandemic isn't easy for anyone, but trying to manage a chronic condition like inflammatory [#arthritis](#) at the same time can be especially challenging:

"The global pandemic is testing our relationships like never before. ... We're losing friends left and right because we have new non-negotiable standards when it comes to dealing with the [#COVID19](#) pandemic."

# Top New Resources

CreakyJoints and the Global Healthy Living Foundation continue to regularly publish new resources every day to help patients with chronic conditions navigate the COVID-19 pandemic.

Our popular “Is It Safe?” series continues to expand as we field more questions and concerns from our patient community. Based on data we collected from our Patient Support Program community polls, these articles examine common reopening activities and feature interviews with top medical experts to help patients decide whether certain activities are safe for them. Because these articles are well-optimized for search engines, they are becoming among our most-trafficked COVID-19 content as people search for answers to these questions. Here are some recent examples.



[Is It Safe to Have Indoor Playdates for Your Kids If You're at High Risk for COVID-19?](#)



[Is It Safe to Carpool with Other People's Kids If You're at High Risk for COVID-19?](#)



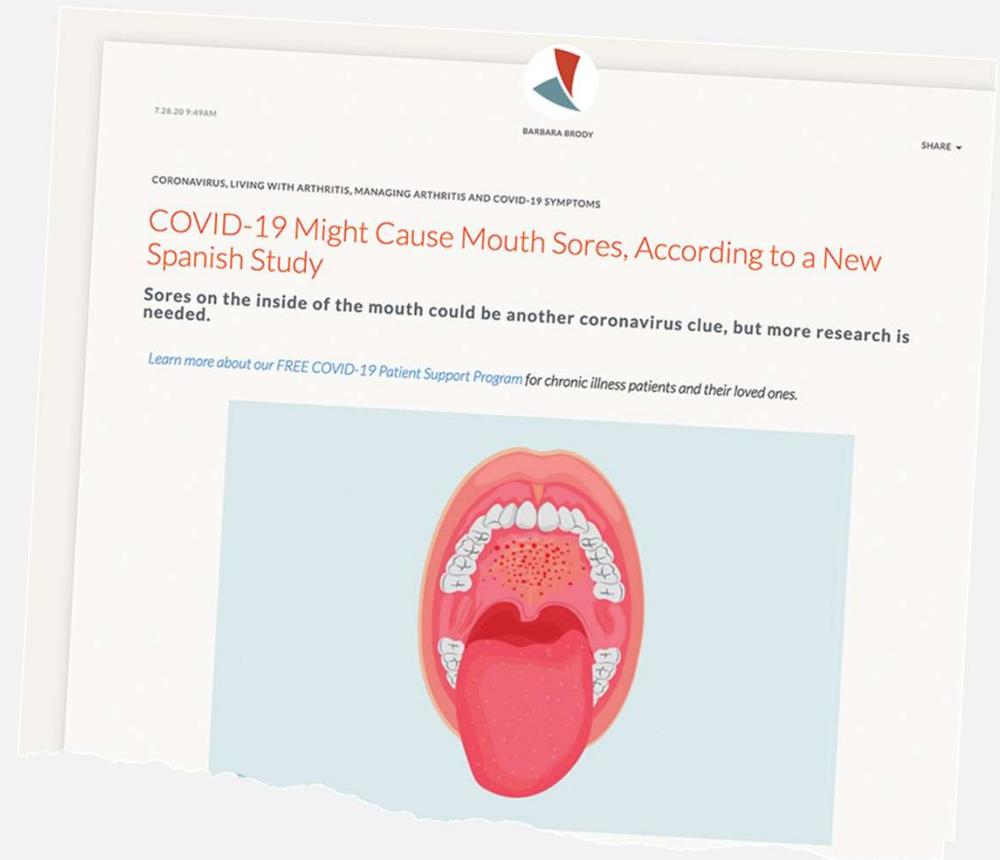
[Is It Safe to Take Public Transportation If You're at High Risk for COVID-19?](#)



[Is It Safe to Fly If You're at High Risk for COVID-19?](#)

## Top New Resources

One of our top COVID stories right now is a news story called "[COVID-19 Might Cause Mouth Sores](#)." Our audience continues to demonstrate interest in understanding potential COVID-19 symptoms, especially ones that are less well-known or understood. We suspect this is due to the fact that chronic illness patients in general struggle to make sense of new/bizarre symptoms and which health conditions may be causing them. Now COVID fears are adding another layer of confusion and worry.



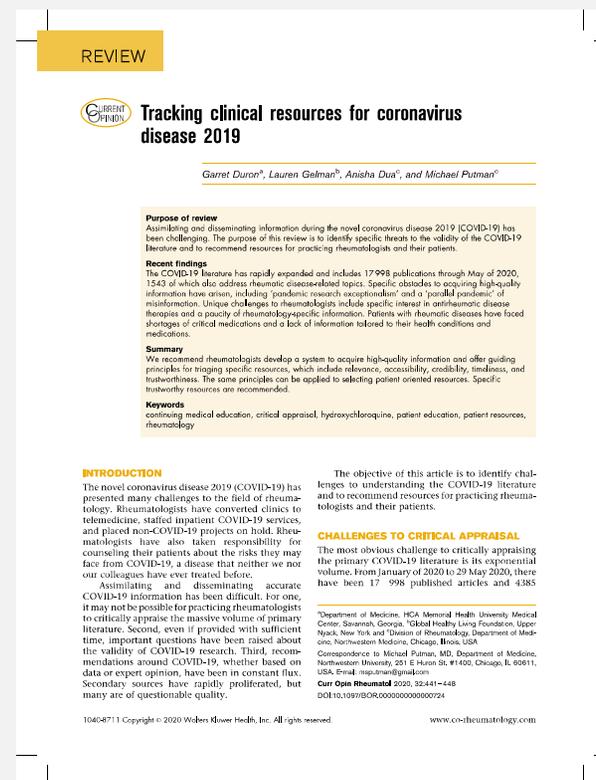
# Helping Health Care Providers Provide Better COVID-19 Patient Education

Lauren Gelman, director of editorial services at the Global Healthy Living Foundation, co-authored a peer-reviewed article in the September issue of *Current Opinion in Rheumatology*, which included a special section called Rheumatological Aspects of COVID-19 curated and edited by key opinion leaders Leonard H. Calabrese, DO, and Cassandra Calabrese, DO. The article is called [Tracking Clinical Resources for Coronavirus Disease 2019](#). Here are more details:

**Goal:** Identify specific threats to the validity of the COVID-19 literature and to recommend resources for practicing rheumatologists and their patients.

**Recent findings:** Patients with rheumatic diseases have faced shortages of critical medications and a lack of information tailored to their health conditions and medications.

**Summary:** We recommend rheumatologists develop a system to acquire high-quality information and offer guiding principles for triaging specific resources, which include relevance, accessibility, credibility, timeliness, and trustworthiness. The same principles can be applied to selecting patient-oriented resources. Specific trustworthy resources are recommended.



The Global Healthy Living Foundation COVID-19 Patient Support Program, including both English and Spanish-language resources, was highlighted prominently as a trusted resource throughout the paper.

## Research Update: Our Autoimmune COVID-19 Study

GHLF's research team has developed a longitudinal patient-powered study called the Arthritis & Rheumatic Disease COVID-19 Project of the Autoimmune Research Collaborative (ARC) to understand the concerns and behaviors of patients with autoimmune, rheumatic, and related conditions during the COVID-19 pandemic.

**At the end of July, we shared preliminary results of our study with partners and sponsors. Below are a few highlights:**

- At the time of the presentation, 2,701 patients had participated in the baseline survey
- Of those, 2,410 patients have an autoimmune disease
  - **1,248 (52%)** have Rheumatoid Arthritis
  - **391 (16%)** have Psoriatic Arthritis
  - **235 (10%)** have Ankylosing Spondylitis
  - **161 (7%)** have Lupus
  - **90 (4%)** have Myositis
  - **285 (12%)** have another autoimmune disease

# Research Update: Our Autoimmune COVID-19 Study

- **Total Numbers:** Since study launch on March 28, 2020, more than 24,000 patients have enrolled in the [Autoimmune COVID-19 Project](#). For the [Arthritis and Rheumatic Disease COVID-19](#) subset of this project, a total of 2,786 patient participants have enrolled. We have fielded the survey in both English and Spanish.
- **Follow Up Surveys:** The study is longitudinal; we recently fielded week 16 of the follow-up survey. Our next follow up survey is at week 20. We closed the baseline recruitment for the English language survey on Friday, July 31, and the Spanish language survey remains open.
- **Spanish Language Survey:** We received IRB approval to provide compensation to all participants of our Spanish-translated survey. Hispanic and Spanish speaking

populations have been disproportionately impacted by the COVID-19 pandemic due to reasons related to health disparities. It is our ethical responsibility to gather data from populations disproportionately affected by the pandemic so we can serve our communities better. Traditionally, Spanish-language populations have not been maximally reached for research opportunities or exposed to education on the value of participating in patient centered research. We felt the responsibility to modify our approach to level the playing field so as to encourage minority populations to participate and make research more inclusive. After several conversations with the Institutional Review Board, a one-time monetary incentive has been offered to Spanish-speaking patient participants who qualify and complete the baseline and initial survey.

# Spanish-Language Update: Partnerships



**CreakyJoints® Español to Emcee the Puerto Rican Foundation for Rheumatic Diseases ReumaExpo 2020 International, Digital Edition**  
[\(link\)](#)



**United Rheumatology offers its members Spanish-language content produced by CreakyJoints Español**



**National alliance shares CreakyJoints Español content**

- OA Action Alliance - The coalition, over 70 member organizations strong, works collectively to advance the recommendations outlined in [The National Public Health Agenda for Osteoarthritis \(2010\)](#)

## We Continue To...



- Research and write Spanish-language articles about COVID-19 and chronic disease management on CreakyJoints Español properties



- Recruit patients into our [Spanish-language COVID-19 Research Registry](#)

# Advocacy Update: Legislative Outreach

**GHLF has initiated virtual meetings with state legislators to share information regarding ongoing issues that our patient community is facing and how they can better support their constituents. Members of our advocacy team recently met with:**

The pandemic has illuminated many policy concerns that impact our patient community. Some of the key topics we are discussing in virtual advocacy meetings include:

- Vaccinations: expanding pharmacists vaccine authority
- COVID-19 vaccination access and information
- Promoting at home infusion services
- Promoting telehealth expansion

Additionally, GHLF continues to submit letters to policymakers around the country to ensure patients have access to care without obstacles. Take a look at our recent comments related to COVID-19 concerns:

- [Letter to Congressional Leadership about Policy Recommendation to Accommodate and protect immunocompromised patients \(immune deficiency sign-on\)](#)
- [California AB 1710, Expanding Pharmacists Ability to Vaccinate](#)



*Representative  
Michelle Mussman  
(D Illinois 56<sup>th</sup>)*



*Assemblyman Herb  
Conaway (D New  
Jersey 7<sup>th</sup>)*



*Senator Arthur Ellis  
(D Maryland 28<sup>th</sup>)*



*Delegate  
Benjamin Brooks  
(D Maryland  
10<sup>th</sup>)*



*Senator Jeff Smith  
(D Wisconsin 93<sup>rd</sup>)*



*Representative  
Padma Kuppa (D  
Michigan 41<sup>st</sup>)*

# Patient Leaders in Our Patient Support Group



## From left:

**Top row:** Jovana Gonzalez Placido (*Scleroderma*), Daniel Garza (*HIV/AIDS*), Susan Herley (*Gout*), Tinu Abayomi-Paul (*Cancer*), Molly Schreiber (*Diabetes*), Terrance Hill (*Sickle Cell Disease*), Peter Morley (*Lupus*)

**Middle row:** Jed Finley (*Ankylosing Spondylitis*), Jamie Holland (*Crohn's Disease*), Charis Hill (*Ankylosing Spondylitis*), Beth Madison (*Lupus*), Jennifer Walker (*Asthma*)

**Bottom row:** Ebby Isbill (*Multiple Sclerosis*), Catherine Charrett-Dykes (*Migraine*), Dawn Gibson (*Ankylosing Spondylitis*), Roxanne Watson (*Heart Disease*), Diane Talbert (*Psoriasis & Psoriatic Arthritis*), Ray Bouchard (*Rheumatoid Arthritis*), Eileen Davidson (*Rheumatoid Arthritis*)

For questions or comments please contact Steven Newmark ([SNEWMARK@GHLF.ORG](mailto:SNEWMARK@GHLF.ORG))