

Staying Socially Active with PI — Especially While Aging

Illness and age are no doubt obstacles to a satisfying social life, but cultivating meaningful social connections is vitally important to your health. Here are our top tips for building a life you love.



By Rachel Maier, MS

DO YOU feel an ache for social connection? I bet you do. Humans are made for it!

But cultivating healthy social connections is easier said than done, especially when you're aging, dealing with a chronic disease such as primary immune deficiency (PI) — or both. The things that used to fill your social calendar might not work for you anymore.

Maybe you are retired and miss daily interactions with co-workers and colleagues; your kids are grown, so little league games are a thing of your past, and you find yourself missing sideline chats with fellow parents; or you lost your spouse, a friend or even the ability to drive; or your aging body makes things you used to enjoy more difficult or impossible. If you also have a PI, things are even more

complicated, and you may find yourself unsure of how to cultivate a fulfilling social life since there is risk involved with being around other people.

Life certainly gets lonelier when your social circle shrinks, and yet prioritizing social activity becomes more and more important as the years wear on. Social connections suffer when activity levels decline, and it's a struggle to know what to do about it. But whatever your hiccup or hinderance — even if it's PI — finding ways to have an active social life is vitally important to aging well and staying healthy.

The Importance of Social Connectedness

If you feel socially stuck, you're not alone. Many aging adults experience social isolation, which is lack of

relationships with others and limited social support or contact. So many things contribute to social isolation, which can cause loneliness and serious health problems.

In January 2023, results from the National Poll on Healthy Aging (NPHA) showed that about one in three adults (34 percent) ages 50 to 80 report feelings of social isolation, and 51 percent of those who have a disability or health condition that they say limits their activity also report they experience a lack of companionship.¹

We asked Cheyenne Crawford, the wellness director at Cedar Lake Village in Johnson County, Kan., to help us understand why social isolation is such a problem for aging adults. According to Crawford, social isolation comes down to feeling discouraged by uncontrollable changes, both physically and socially, that limit people's ability to live the way they really want to live. The details of their life change — they retire, their relationships change, their body does funny things — and their social circle naturally gets smaller.

“As we age, it can become more difficult to have consistent social interactions,” explains Crawford. “Getting to social activities outside of the house becomes more and more difficult. Bodily changes such as hearing loss even cause a whole new feeling of isolation: Not being able to hear conversations or things going on around you may be embarrassing or frustrating and may cause a pullback in socializing. Vision loss is the same: If someone is used to playing card games with a group of friends or is in a book club, they may feel like they are unable to attend those events. Pain and other common health problems can be very discouraging to seniors, too. For example, if they are having trouble sleeping at night, they may not have the energy to go to an activity that they would normally be able to attend.”

But despite the hardship or inconvenience, Crawford emphasizes staying socially active is vitally important to overall health: “Socializing is one of the most important factors for seniors' lives. It can affect both mental and physical aspects of health, along with quality of life.”

Unlike social isolation, social connectedness is healthy and important for mental well-being, and by extension, physical health, too. It combats loneliness by giving people a sense of belonging and being cared for, valued and supported.² People who are socially connected and have

stable, supportive relationships are more likely to make healthy choices, have better mental and physical health outcomes and are better able to cope with hard times, stress, anxiety and depression.²

Indeed, research shows social connectedness dramatically improves the health of older adults. In fact, socially isolated and/or lonely older adults are at a higher risk for heart disease, depression and cognitive decline, but making new social connections later in life helps older adults boost their self-esteem, reduce their feelings of loneliness and increase physical activity. When people find activities that are meaningful to them, they tend to live longer, be in better moods and live with a sense of purpose.³

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The Problem of PI

But there is an elephant in the room when it comes to cultivating a healthy social life: How can people with compromised immune systems stay socially active — and safe? (After all, those with PIs were social distancing before it was even a thing.) Spending time with other people carries an inherent risk. If you're someone with a compromised immune system, understandably the last thing you want to do is expose yourself to pathogens that could make you seriously ill.

Perhaps not surprisingly, people with chronic illnesses are more apt to feel socially isolated. “Those living with chronic illness are the most prone to social isolation. Being in constant pain really discourages someone from participating in activities. Another concern is worry about catching an illness from others at social activities,” adds Crawford.

However, have you considered this startling statistic? Nearly one in three people with a long-term physical health condition also has a mental health problem, most often depression or anxiety.⁴ What's more, people with chronic diseases such as PI are especially prone to mental health problems. And, people with PI are 91 percent more likely to



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What is HyQvia®?

HyQvia [Immune Globulin Infusion 10% (Human) with Recombinant Human Hyaluronidase] is a liquid medicine that is given under the skin (subcutaneously) to treat primary immunodeficiency (PI) in people 2 years and older.

IMPORTANT SAFETY INFORMATION

What is the most important information that I should know about HyQvia?

- HyQvia can cause blood clots.
- Call your healthcare professional (HCP) if you have pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s), unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, numbness or weakness on one side of the body.
- Your HCP may perform blood tests regularly to check your IgG level.
- Do not infuse HyQvia into or around an infected or red swollen area because it can cause infection to spread.

Who should not take HyQvia?

Do not take HyQvia if you:

- Are allergic to IgG, hyaluronidase, other blood products, or any ingredient in HyQvia.

What should I avoid while taking HyQvia?

- HyQvia can make vaccines (like measles/mumps/rubella or chickenpox vaccines) not work as well for you. Before you get any vaccines, tell your HCP that you take HyQvia.

What should I tell my HCP before I start using or while using HyQvia?

Tell your HCP if you:

- Have or had any kidney, liver, or heart problems or history of blood clots because HyQvia can make these problems worse.
- Have IgA deficiency or a history of severe allergic reactions to IgG or other blood products.
- Are pregnant, trying to become pregnant or are breast feeding. It is not known whether HyQvia can harm the unborn baby or breastfed infant.

What are the possible or reasonably likely side effects of HyQvia?

HyQvia can cause serious side effects. If any of the following problems occur after starting HyQvia, stop the infusion immediately and contact your HCP or call emergency services:

- Hives, swelling in the mouth or throat, itching, trouble breathing, wheezing, fainting or dizziness. These could be signs of a serious allergic reaction.
- Bad headache with nausea, vomiting, stiff neck, fever, and sensitivity to light. These could be signs of irritation and swelling of the lining around your brain.
- Reduced urination, sudden weight gain, or swelling in your legs. These could be signs of a kidney problem.
- Pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s). These could be signs of a blood clot.
- Brown or red urine, fast heart rate, yellow skin or eyes. These could be signs of a liver or blood problem.

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0.025 infections per year



This is equivalent to 25 acute serious bacterial infections (ASBIs) out of 1,000 patients over the course of the 12-month study period.

The FDA standard for efficacy—that is, if an immunoglobulin works—is less than 1 ASBI per year. In the clinical trial, people taking HyQvia experienced significantly less than that.

- HyQvia was studied in a clinical trial of 83 people with PI, with the main goal of measuring how many acute serious bacterial infections (ASBIs) they experienced over the course of 1 year

- ASBIs are short-term but serious infections caused by bacteria that require immediate medical care

- ASBIs included 2 episodes of pneumonia, both treated as outpatients with oral antibiotics. An additional episode of pneumonia requiring hospitalization occurred during the ramp-up

- The most common general (systemic) side effects were headache, antibody formation against hyaluronidase (Hy), fatigue, nausea, fever, and vomiting. The most common side effects at the infusion site (local) were pain, redness, swelling, and itching



0 days in the hospital per year

There was a mean of 0.037 days spent in the hospital due to infection during the study.



<4 days off work or school per year

On average, patients taking HyQvia missed 3.31 days of work or school due to an infection.

*Between infusions, based on administration every 3 or 4 weeks.
subQ IG=subcutaneous immune globulin.

IMPORTANT SAFETY INFORMATION (continued)

- Chest pain or trouble breathing, blue lips or extremities. These could be signs of a serious heart or lung problem.
- Fever over 100°F. This could be a sign of an infection.

After HyQvia infusion a temporary, soft swelling may occur around the infusion site, which may last 1 to 3 days, due to the volume of fluid infused. The following possible side effects may occur at the site of infusion and generally go away within a few hours, and are less likely after the first few infusions.

- Mild or moderate pain
- Redness
- Swelling
- Itching

The most common side effects of HyQvia are:

- Headache
- Fatigue
- Nausea
- Fever
- Vomiting

Antibodies to the hyaluronidase component of HyQvia were formed in some patients taking HyQvia. It is not known if there is any long-term effect. In theory, these antibodies could react with your body's own hyaluronidase (PH20). PH20 is present in the male reproductive tract. So far, these antibodies have not been associated with increased or new side-effects.

These are not all the possible side effects. Talk to your HCP about any side effect that bothers you or that does not go away.

Please see Important Facts about HyQvia on the following page.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

What makes HyQvia different? Scan the code!



You can always visit HyQvia.com/why-hyqvia to learn what makes HyQvia different, and so much more.



IMPORTANT FACTS about HYQVIA (Hi-Q-via) [Immune Globulin Infusion 10% (Human) with Recombinant Human Hyaluronidase] Solution, for subcutaneous administration

What is the most important information I should know about HYQVIA?
<ul style="list-style-type: none"> • HYQVIA can cause blood clots. • Call your healthcare provider (HCP) if you have pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s), unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, numbness or weakness on one side of the body. • Your HCP may perform blood tests regularly to check your IgG level. • Do not infuse HYQVIA into or around an infected or swollen area because it can cause infection to spread.
What is HYQVIA?
<p>HYQVIA is a liquid medicine containing immune globulin and Recombinant Human Hyaluronidase. HYQVIA is given under the skin (subcutaneously) to treat primary immunodeficiency (PI) in people 2 years of age and older. HYQVIA contains IgG antibodies, collected from human plasma donated by healthy people. The antibodies help your body to fight off bacterial and viral infections. The hyaluronidase part of HYQVIA helps more of the immune globulin get absorbed into the body to fight infection.</p>
What should I tell my HCP before I start using or while using HYQVIA?
<p>Tell your HCP if you:</p> <ul style="list-style-type: none"> • Have or had any kidney, liver, or heart problems or history of blood clots because HYQVIA can make these problems worse. • Have IgA deficiency or a history of severe allergic reactions to IgG or other blood products. • Are pregnant, trying to become pregnant, or are breastfeeding. It is not known whether HYQVIA can harm the unborn baby or breastfed infant.
Who should not take HYQVIA?
<ul style="list-style-type: none"> • Do not take HYQVIA if you are allergic to IgG, hyaluronidase, other blood products, or any ingredient in HYQVIA.
How should I take HYQVIA?
<ul style="list-style-type: none"> • HYQVIA is infused under the skin (subcutaneously) up to once every 4 weeks. • You can get HYQVIA at your HCP's office, clinic, or hospital. • You can use HYQVIA at home. You and your HCP will decide if home self-infusion is right for you.
What are the possible or reasonably likely side effects of HYQVIA?
<p>After HYQVIA infusion a temporary, soft swelling may occur around the infusion site, which may last 1 to 3 days, due to the volume of fluid infused.</p> <p>The following local reactions may occur at the site of infusion and generally go away in a few hours. Local reactions are less likely after the first few infusions.</p> <ul style="list-style-type: none"> • Mild or moderate pain • Redness • Swelling • Itching <p>The most common side effects of HYQVIA are: headache, vomiting, fatigue, nausea, and fever.</p>

<p>Antibodies to the hyaluronidase component of HYQVIA were formed in some patients taking HYQVIA. It is not known if there is any long-term effect. In theory, these antibodies could react with your body's own PH20. PH20 is present in the male reproductive tract. So far, these antibodies have not been associated with increased or new side effects.</p> <p>Call your HCP or go to your emergency department right away if you get:</p> <ul style="list-style-type: none"> • Hives, swelling in the mouth or throat, itching, trouble breathing, wheezing, fainting or dizziness. These could be signs of a serious allergic reaction. • Bad headache with nausea, vomiting, stiff neck, fever, and sensitivity to light. These could be signs of irritation and swelling of the lining around your brain. • Reduced urination, sudden weight gain, or swelling in your legs. These could be signs of a kidney problem. • Pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s). These could be signs of a blood clot. • Brown or red urine, fast heart rate, yellow skin or eyes. These could be signs of a liver or blood problem. • Chest pain or trouble breathing, blue lips or extremities. These could be signs of a serious heart or lung problem. <p>These are not all of the possible side effects for HYQVIA. You can ask your HCP for information that is provided to HCPs. Talk to your HCP about any side effects that bother you or that don't go away.</p>
How do I store HYQVIA?
<p>Store HYQVIA refrigerated or at room temperature.</p> <ul style="list-style-type: none"> • You can store HYQVIA in the refrigerator (36°F to 46°F [2°C to 8°C]) for up to 36 months. • You can store HYQVIA at room temperature (up to 77°F [25°C]) for up to 3 months during the first 24 months from the date of manufacturing (Mfg Date) printed on the carton. • Do not return HYQVIA to the refrigerator if you take it out to room temperature. <p>Check the expiration date on the carton and vial label. Do not use HYQVIA after the expiration date.</p> <p>Do not freeze.</p> <p>Protect from light. You can use the original HYQVIA containers to protect it from light.</p>
How do I get more information about HYQVIA?
<p>The risk information provided here is not comprehensive. To learn more, talk about HYQVIA with your HCP or pharmacist. The FDA-approved Full Prescribing Information, including Information for Patients, can be found at www.HYQVIA.com or by calling 1-877-TAKEDA7 (1-877-825-3327).</p>

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have a mental health disorder compared to those without it.⁵

While it is best to stay home when you know there's a very real risk of exposing yourself to unwanted illness (such as visiting a friend who you know is sick) or when you're not feeling well yourself, it is equally important to know that over time, social isolation and loneliness can make you sick, too, because they put you at higher risk for high blood pressure, heart disease, obesity, a weakened immune system, anxiety, depression, cognitive decline, Alzheimer's disease and even death.³

Although being around others in a social setting does pose a risk, the benefits of social activity may outweigh the risk. According to Crawford, "There have been studies to show that socialization can be beneficial for one's immune system. There are precautions that can be taken to help mitigate those risks: possibly wearing a mask, washing hands, etc. But the neat thing is in this day and age, you do not necessarily have to leave your house for socialization."

If the idea of being around other people makes you nervous, remember: Over time, not being around other people could make you sick, too. So, whether you connect with a limited amount of people you trust, meet new people online or have a lot of friends out in the community, the point is: Stay active and get connected! It's vitally important to your health, too.

10 Ways to Stay Socially Active

1) *Figure out what's holding you back.* What barriers do you face? Does your budget, lack of transportation or a physical limitation keep you isolated? Or maybe a slew of "What if's" are holding you back: What if I'm exposed to something that makes me really sick? What if I get sick beforehand and have to cancel my plans? What if I can't hear what's going on? What if I can't get to a bathroom fast enough?

Obstacles are real, but instead of deciding you can't do anything, think about ways you can do something. Talk about it with someone you trust (a spouse, adult child, caretaker, friend). Tell them about the things you would like to do and the obstacles that make it difficult to do them. Ask them to help you think of ways to work around the problems. For example, if urinary incontinence makes leaving the house hard, consider wearing leak-absorbent underwear (such

as Knix or Thinx) while you're out. If you love ballroom dancing but arthritis makes it too painful, consider taking an aqua dance class instead. If vision loss prevents you from joining a book club, participate by listening to an audio version of the book.

2) *Stay in touch with someone you already know.* It could be a family member or friend you know well, or even an acquaintance you would like to get to know better. Whoever it is, pick up the phone, send a quick text or write a handwritten letter. Reach out and invite that person to join you for a regular check-in over a cup of coffee, lunch, a walk through the park or, if you can't meet in person, a phone call or video chat.

People with PI are 91 percent more likely to have a mental health disorder compared to those without it.

3) *Seek out community centers.* According to Crawford, community centers and senior centers in your city or county always have activities going on, and they're especially helpful to adults ages 55-plus with their peers. If you have access to the Internet, search for local calendars online. If you don't have Internet access, or if you prefer to speak to someone in person, pop in for a visit or call and request information be sent to you by mail.

4) *Try something new.* Add something new to your social calendar. Perhaps there's an activity you've always wanted to do, but just haven't gotten around to it. Do yourself a favor and sign up for the class, buy tickets to the event or commit to a volunteer opportunity. Not sure where to start? Check your community event calendar for local options. Find something that interests you, whether it is in-person or online, and sign up to attend. Bring a friend or family member along for the fun!

5) *Pursue a hobby.* You know that hobby you love? Seek out groups of others who enjoy it, too, and attend events they sponsor. (Don't have a hobby yet? Take a quiz to discover something new! Try [HobbyFinder.io](https://www.hobbyfinder.io).) You'll increase your chances of meeting people with whom you have things in common, and shared experiences naturally cultivate connection. If in-person events don't work for you, explore

online alternatives. “We have a resident here who plays virtual bridge with her family every Sunday,” said Crawford, “and I have known of some residents whose book clubs also met virtually.”

6) *Volunteer your time and talents.* Think about causes important to you, and inquire about ways to get involved. Perhaps politics are your thing: Sign up to help at your local polling place. Are you an animal lover? Contact a local shelter and ask how you can get involved. You can even combine your love of travel with volunteering your time and effort through Global Volunteers, an organization connecting seniors, travel and service projects. (See globalvolunteers.org for more information.)

7) *Make friends online.* Connect with others you wouldn't otherwise meet using the power of the Internet. Try a lesser-known friend-finding app such as [Friendrapp.com](https://friendrapp.com), [Nextdoor.com](https://nextdoor.com), [Skout.com](https://skout.com) or [Meetup.com](https://meetup.com) to help you discover “your people” — the ones who share similar interests or life experiences and with whom you may develop a lasting friendship. If you have PI, get involved with the Immune Deficiency Foundation (IDF) Peer Support Program as a mentor, or join an IDF Get Connected Group to connect with other patients with PI, share experiences and offer support to each other. (Go to primaryimmune.org/living-primary-immunodeficiency/get-support/peer-support-program for more information.)

8) *Say yes.* When someone invites you somewhere, accept the invitation. Put it on your calendar and plan to attend, and then work out a plan to actually go later. (For example, if your granddaughter has a dance recital but you can't drive yourself to it, mark your calendar and then talk to friends and family to figure out how you'll get there.) True, you might end up having to cancel, but there's also a good chance you will be able to go, too! Don't miss out on an opportunity based on “What if?”

9) *Get a job.* Meaningful, productive work helps cultivate a sense of purpose. If you're not currently working, consider getting a job since it can provide a place to interact with others on a regular basis. If you are interested and able, plenty of in-person full- and part-time jobs are available that may align with your interests and/or natural talents. If you can't commit to leaving the house, explore remote jobs that can be done on your computer such as online teaching (try [Outschool.com](https://outschool.com)), tutoring, online coaching, customer service or telehealth nurse. Or, check out [FlexJobs.com](https://flexjobs.com) for more inspiration.


10) *Join an exercise group.* Sign up for a fitness class, take a

water aerobics class or join a walking group or biking club. “These are amazing places to join a community and to build friendships!” says Crawford. If you can't get out of the house, silversneakers.com offers a wealth of live and on-demand online classes and workshops for aging adults, as well as a list of in-person classes in your area. There's even an app for on-the-go!

It's Work, but It's Worth It

Engaging in social activities is beneficial for mental health as people age. “Not having someone to talk to, relate to or connect with can cause feelings of loneliness,” says Crawford. “Loneliness can spiral into depression and anxiety. But staying busy and having activities to look forward to and to feel ‘normal’ is important for mental health. Social activities are fun, and they also take brain power: Conversations and games can both help with a decrease in cognitive decline. And, volunteering makes people feel needed.” Since those with PI are at a heightened risk for mental health disorders, it's even more important for them to prioritize staying social and cultivating meaningful connections.

Granted, sometimes you'll still have to say no (such as when a friend or family member asks you come over to visit them while they're sick or if an event happens on the same day as an infusion), but sometimes, saying yes is not only possible, but good for you (such as when a friend invites you to meet for coffee to chat about a book you both just finished reading).

Remember: Staying socially active as you age — especially when you have PI — is vitally important to your overall health and wellness. Yes, medicine adherence, a healthy diet, adequate sleep, plenty of fresh air and exercise are all key components to staying healthy, but so is social activity. Do something good for yourself and pick one small step to take today to start cultivating a social life that brings you joy. With time, effort and creativity, it will be worth it! 

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