

## Art for My Heart

It had been a long, cold winter in Colorado and even in April there were few signs of spring. I was diagnosed with class IV idiopathic PAH in 2008, and the isolation and lack of social interaction in winter gets to be a challenge for me mentally. So on one of my grocery shopping trips, I stopped by a craft store and wandered through the aisles to see what I could find. I had never been an “artist” and many of the crafts I had done in the past (knitting, needlework, etc.) were becoming difficult for me because of arthritis.

As I was walking through the paints, a little watercolor pencil kit caught my eye. It had eight pencils, a good quality brush and an instruction book. On a whim I picked it up, and that evening I started going through the first lesson. It was fun, took very little energy and didn’t make a mess. Just the right combination for me!

After going through the lessons, I bought some watercolor paper and did a few little paintings for my grandchildren. I was enjoying it so much I decided to do more studying about watercolor technique, so I checked out some books and videos from the library and watched lessons on YouTube. I bought some inexpensive watercolor paints and did my first real paintings at the end of April and first weeks of May (still snowing and cold).

Over the next weeks, I realized this was more than a passing interest to get me through until summer. I purchased better quality paints, paper and brushes and even joined a watercolor society. I now look forward to getting up in the morning and painting, even if it’s just a simple pen and ink with watercolor wash. My “studio” is a 5’x6’ space in my small condo (just a table next to a window with good natural light most of the day).

It has definitely made a difference in my outlook and mental and physical energy. When you have severe PAH, it’s easy to want to give up. Once I started painting, I began to realize that this was becoming a significant part of my legacy. I took photos of my sketches and paintings and saved them in a file so that they would outlast me.

Because of a genetic disease that keeps me from metabolizing drugs properly, I don’t tolerate any of the medications normally prescribed for PAH. Of course that pretty much seals your fate when you’re in advanced stages. Applying my background in nutrition and biochemistry, I did a lot of research and came up with



*Janet painted "Happy the Beagle" in May 2011*

a treatment plan using supplements and herbs. My right ventricular systolic pressure (RVSP) improved, and I wasn’t getting worse, but my functional capacity was still very limited and my oxygen saturation would drop into the low 80s on exertion.

At first, I thought perhaps I was imagining things, but in late spring it seemed like my heart function was improving. I could go up the stairs to my apartment instead of using the elevator all the time and I didn’t see stars when I got to the top. I ventured out on a few

hikes with my husband; the first was fairly easy but quite an accomplishment. The second was much more ambitious. We were at a high altitude, and we hiked to a fishing lake on a rough trail. My husband carried my oxygen concentrator, and I was “tethered” by the tubing, walking behind him. When we got to the lake, I took out a tiny watercolor field kit and painted the beautiful scenery while he fished. It felt so wonderful to be doing something normal again!

A few weeks ago I had my first echo since I started painting. To our surprise my RVSP had dropped into the 50s. My doctor and the cardiologist thought it must have been an error in the measurements, but I know better. I can feel the difference. Is it a coincidence? I don’t think so. The American Art Therapy Association has documented the benefits of art as a healing tool for all types of mental and physical conditions, including pulmonary diseases.

I would encourage all of you who think you are artistically challenged to give it try. It’s not about producing a masterpiece or winning a show. Art is expressing your feelings, communicating with shapes and color and light, and sharing your own unique perspective of the world around you. Here are a few tips that might help you get started:

- 1. Choose ONLY non-toxic materials.** I picked watercolor as my medium because you don’t need any solvents to dilute the paint or clean brushes. However, even with watercolor, some of the pigments used are considered toxic (cadmium and cobalt most notably). There are kits and tubes you can buy that are certified non-toxic. Look for the ACMI label. We need to do everything we can to protect our lungs, and unfortunately art supplies often contain VOCs

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(volatile organic compounds) and hydrocarbons that can compromise both lung and liver function. Even naturally occurring compounds like ammonia, turpentine and alcohol can be very hard on our lungs and worsen PAH.

2. **Take advantage of online learning opportunities and library resources.** As mentioned earlier, I watched many instructional videos on YouTube, and just recently got a subscription to ArtistNetwork.TV, which offers videos of workshops with well-known artists in all mediums.
3. **Look for community resources.** If you are able to get out and attend classes, community colleges and adult education programs are a great way to develop your skills. Most senior centers offer free or low-cost art classes. I just started attending a live model class once a week at my neighborhood center to get experience drawing portraits. We have a great time and everyone just chips in \$3 to pay the model.
4. **Communicate with other artists.** The greatest resource for me has been a website called [www.WetCanvas.com](http://www.WetCanvas.com). There are forums for every medium and subject area. I have learned so much from this wonderful online community and made some great cyber-friends from all over the world.

You can post your artwork (they welcome beginners and give helpful tips for improving), participate in monthly challenges to help you set a goal, and just chat with people of all abilities and disabilities!

5. **Share your work with others.** Art is about communicating. If friends and family laugh at your first attempts, just ignore it and keep going. Find a group of people online or in your community who understand the value of art therapy and who will encourage you, even if it seems primitive and very beginner-ish! Make sure you save at least some of your artwork and photograph or scan and file it digitally if possible.

As I write this, I'm looking forward to a few hours of painting today and a visit to a local watercolor exhibition with a friend who is also disabled and interested in art therapy. I hope you'll give it a try — your heart may thank you in more ways than one! ♦

*By Janet Stone, PH Patient*

To read Janet's article in its entirety, visit [www.PHAssociation.org/OurJourneys/JanetStone](http://www.PHAssociation.org/OurJourneys/JanetStone). To view a workshop on creative expression from PHA's 9<sup>th</sup> International PH Conference in 2010, visit [www.PHAssociation.org/WordsForWellbeing](http://www.PHAssociation.org/WordsForWellbeing).

## Show Your Healthcare Who's Boss

### Introducing PHA's Empowered Patient Online Toolkit

Studies show that patients who take the time to get and stay organized have an easier time following their medication regimens, alleviating symptoms and actually helping them feel better. This is no news to long-term PH patients and caregivers, many of whom have developed elaborate strategies for tracking medication dosages, nurses' pager numbers, insurance plan information, appointment calendars and much more.



Drawing on the collective wisdom of the PH community, PHA has assembled some of the most useful tools, templates and checklists used by PH patients and medical professionals in our brand-new Empowered Patient Online Toolkit. The toolkit includes a range of resources that patients and caregivers can download

in PDF format, personalize, and then either save to an electronic flash drive or print out to create a personalized medical binder.

#### The Empowered Patient Online Toolkit can help you:

- Summarize your medical and family history for new doctors
- Be prepared in case of an emergency room visit
- Track your medications and medical team contacts
- Prepare for doctor's visits
- Record symptoms and concerns between medical appointments
- Summarize important information from appointments and hospital visits
- Keep your insurance information organized
- And more!

Get started at  
[www.PHAssociation.org/OnlineToolkit](http://www.PHAssociation.org/OnlineToolkit)