

COMMENTARY

How I got started in advocacy

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Rheumatology News and the Coalition of State Rheumatology Organizations have partnered together to keep rheumatologists regularly informed on the advocacy issues of the day and perhaps inspire those who may be on the fence about finding “room” in their lives for action. This inaugural piece tells how CSRO President Dr. Madelaine (Mattie) A. Feldman views advocacy and how she found her way to action.

As a rheumatologist in private practice for 30 years, with husband and kids (and now grandkids), an active social life, and an exercise regimen, I realized if I were to become active in advocacy I would have to make room for it in my busy schedule. We all come up against the question of where will we find the time for a new hobby, exercise, joining a new organization, or even just eating right? Next comes the priority list discussion. How important is advocacy for my patients, my specialty, and my profession? Ultimately, how important is it for me? Where did that desire to get involved even come from? Why have I become so passionate about the issues?



Dr. Madelaine Feldman

For me, the answer to these questions goes back to the 1960s when I was growing up in New Orleans. My mom participated in civil rights protests, which did not make our family popular in the neighborhood, back when the KKK put flyers on everyone's screen door. My mother didn't care and told me that, no matter what people said, it was our duty to stand up for what was right. That was a long time ago and sadly my mom passed away just a year after I was old enough to vote. Her words have stayed with me and are more important now than ever.

Striving for justice despite how formidable the foe is requires an inner knowing that what you are doing is meaningful and will make a difference maybe not now, maybe not next year. At some point you must believe that your efforts will create a change for the better, small as it may be. My "saying" on Twitter ([@MattieRheumMD](https://twitter.com/mattierheummd) <<https://twitter.com/mattierheummd>>) is "I'll keep doing what I'm doing until my cynicism catches up to my passion."

The story about my mom is just one of the many stories in my life taking me to where I am today. We all have them. I think the reason many of us go into rheumatology may be similar to the reasoning that leads one to advocacy efforts. At this point in time we can't yet offer a cure, but we can point to a path that leads to improvements in the lives of our patients. I have to remind myself

The four Ps of advocacy

Living with compromise is hard, particularly when working within a system that needs a complete overhaul. Still, compromise is the key to getting anything done. **Compromise** is one of the four Ps of advocacy. I realize that compromise doesn't start with a P, but it is such an integral part of advocacy, I am making allowances for it. The other Ps include **patience**, **persistence/perseverance**, and **passion**. I'm sure there are many others that could be part of the P family, like planning and performance, but let's stick with these.

You don't need to have all of these qualities when you start on the road to action in advocacy. For example, my **passion** came first. It developed when my patients could not get access to the treatments they needed. For many reasons, the medications were either unavailable (i.e., not on formulary, tiered very high) or unaffordable (i.e., copay too high, deductible too high). My passion deepened when I saw the hypocrisy within the drug-supply channel and the mistruths being told by those who profit from this channel. It wasn't the "profit" part that bothered me, as I'm a believer in the free market. But this was not free market, and the companies were actually profiteering on the backs of my patients and justifying it by claiming they were saving the health care system billions of dollars. The fallacy of that claim and the players in this broken system are stories for another day.

Persistence came next for me. If you let up on the message, things might not only stay the same but could get worse. **Perseverance** is part of persistence because you need it to keep knocking on the same door even after that door is metaphorically (hopefully not literally) slammed in your face. Often, I will feel like a broken record and think that everyone has already heard the issues, not

be heard before it is fully comprehended.

Patience is one of the more difficult attributes to practice when you want action. I want things to happen yesterday – not tomorrow and definitely not next year. I have learned that the wheels of change turn quite slowly in this arena, sometimes pausing for inordinately long periods of time. I realize now that during the long wait, new facts can arise, allowing me to shape a different advocacy approach, one that ultimately bolsters my case. It still is very difficult to hear that a piece of legislation that seemed to be moving forward suddenly died and won't be heard again until the next session. With patience you move forward with a smile, maybe a half-hearted one, but a smile nonetheless. This just makes life better.

Then there is **compromise**. This took me the longest to understand, particularly on the issues where my passion ran the deepest. Here is where passion could potentially get in the way of action. Feeling very strongly about an issue makes it difficult to let any piece of your ideal end result fall by the wayside. Here is where the saying “the perfect is the enemy of the good” comes into play. Just because you can't have it all, doesn't mean you can't do good by achieving just part of what you have been striving for. Remember if you seek perfection, without compromise, you may lose the entire battle. Is there such a thing as compromising too much? I think so, but that may just be my passion speaking.

Rheumatology News and the Coalition of State Rheumatology Organizations started this column to keep you informed about current advocacy issues in rheumatology and perhaps inspire those who may be on the fence about finding “room” in their lives for action.

Advocacy doesn't have to take up much room in your life. It can be as simple as clicking on CSRO.info/map <<http://CSRO.info/map>> , finding your state, and

columns). Or maybe just finding the time to read this column is all the action you have room for. We all have different amounts of space for any particular activity in our busy lives. It seems one of my stories from childhood created that space for advocacy in my life. I guess you could say it created a “Rheum” for Action.

Dr. Feldman is a rheumatologist in private practice with The Rheumatology Group in New Orleans. She is President of the CSRO <<https://csro.info/>> , chair of the Alliance for Safe Biologic Medicines, and a past member of the American College of Rheumatology insurance subcommittee. You can reach her at rhnews@mdedge.com.

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