

**IPRCC Meeting on November 16, 2018**

**Invited Remarks on IPRCC Tenure and Pain Management Best Practices Task Force**

*Cindy Steinberg*

In the three years that I have served on the IPRCC, I have to say that this is the most hopeful time to be an advocate for people living with chronic pain. I equate basic research with hope. Hope that we will one day fully understand the neurobiological mechanisms of pathological pain in the human body. Hope that that knowledge will lead to the discovery of molecules to actually cure chronic pain.

The enormous investment that Congress has made in the pain portion of the HEAL initiative and the Common Fund project studying the transition from acute to chronic pain is incredibly exciting. I am truly grateful for these substantial investments.

And yet, sometimes I wonder if pain is so fundamental and protective to the human species that, from an evolutionary standpoint, it is “super redundant”. In other words, is there a multiplicity of pain-producing mechanisms and perhaps they are connected in the body somehow that all produce pain once they get activated making a complete cure unattainable.

Irrespective of that thought, the recent investments we are making in research are likely to lead to new understanding, new treatments and incremental progress in the fight against chronic pain.

But for now and the foreseeable future, the reality is that chronic pain is a terrible waste of human potential, a waste of healthcare expenditures that condemns many Americans to live a bleak, lonely life of tremendous suffering.

Thanks to Chad and his associates’ work, to support from Linda and the NIH and to the National Pain Strategy, we have recent and more precise data on the number of Americans living with chronic pain. And it is a huge number by any measure – 50 million. More concerning is the number with high-impact chronic pain – pain that interferes with daily activities, the ability to work and to socialize. 19.6 million Americans live with high-impact and in many cases disabling pain.

In my work as an advocate these past 18 years, I have met hundreds of people living with chronic pain and every one of them has the same story to tell. Every one of them has had to see, at minimum 4 or 5 doctors, until they found someone who could help them if they ever did. Most of them have had the experience of not being believed about their pain or they have been accused of exaggerating, malingering or drug-seeking.

This grossly inadequate treatment of people living with chronic pain in this country does not have to be this way. Although, we don’t have a magic bullet that will take away anyone’s pain and we are far from having a cure, we do know enough about how to manage pain and how to manage the psychological and social impact of persistent pain to substantially reduce its burden....

and that is the charge of the Pain Management Best Practices Task Force or PMTF as we call it.

The PMTF has been tasked by Congress with identifying gaps and inconsistencies in current practice and recommending how to ameliorate them. The 28 appointees including Linda from NIH, Sharon from FDA and 5 other federal members were chosen as leaders in the field of pain management.

The PMTF received over 3,000 comments to date even before we have issued a report. The overwhelming majority of them were from pain patients. Nearly 80% talked about their inability to access treatment that had been helping them – predominantly opioids, 60% said their functionality had decreased as a result and shockingly and sadly 25% mentioned considering suicide.

We just heard from Dr. Singh, who as you know is the Chair of the PMTF and is an experienced pain physician, whom we are so fortunate to have leading this effort.

I applaud her for keeping the focus on pain patients over the last 6 months of our work and I believe the report and recommendations will reflect a patient-centered approach.

So what do I mean by “patient-centered” in this context?

The recommendations stress the necessity of *individualization of care* in the selection of therapies tried, in the consideration of risks and benefits of therapies, in the duration of treatment, in the optimal dosing of medication and so on.

A significant portion of the report focuses on pain in *special populations* of patients including the elderly, children, military and veterans, women, pregnancy, African Americans, Native American, chronic relapsing conditions and others.

I am pleased that the report courageously addresses timely, difficult yet important topics in pain management such as opioids, stigma, access to care and mental health comorbidities in a rational, balanced and compassionate manner.

As we learned with the National Pain Strategy, all the brainpower, person hours and sheer effort that goes into reports such as this one only really changes patients’ lives for the better if it is implemented. It will be critical for agencies called out in the report to embrace those recommendations that pertain to them. I hope those of you representing those agencies can provide advice and support in that regard. It will also be important for advocates in professional societies and patient groups to register their support with their representatives in Congress.

The draft report will be released for public comment likely in early December (as Dr. Singh mentioned.) I encourage all of you to please comment on it so the final draft can reflect those comments and the

document can be as important a milestone in pain management as the IOM report and the NPS before it. It has been a pleasure to serve on this committee these past three years.