

## **CAPSTONE PROJECT**

### **IASP Pain in Intellectual and Developmental Disabilities SIG Conference**

#### **Background**

The Pain in Intellectual and Developmental Disabilities Special Interest Group (PIDDSIG) of the International Association for the Study of Pain (IASP) was ratified in 2020 after several attempts to promote the need for this distinct SIG. Founding members of the SIG met informally for the first time at the world congress in Argentina in 2014. As an officer of PIDDSIG I support the social media account, edit newsletters, generate ideas for webinars and will participate in chairing and speaking at the pre-conference workshop at the IASP world congress. The PIDDSIG executive committee has discussed the importance of gathering the small but dedicated group of scientists, medical experts, and leaders in the field of pain in intellectual and developmental disabilities (IDD) for a conference. However, there has been little action taken to make this a reality due to competing priorities. There is an opportunity to take on a leadership role and organize and host this conference.

#### **Goal**

If chosen for the leadership academy, my goal would be to orchestrate the first conference of the IASP PIDDSIG. I would do so in collaboration with the PIDDSIG executive committee but would lead the planning and preparation. I would organize the agenda and invite speakers and attendees. While deferring to the PIDDSIG chair to lead aspects of the in-person meeting, I would oversee the event and move the attendees through the agenda and ensure the conference runs smoothly.

#### **Conference Program**

It would be my role throughout the planning process to gather input from the PIDDSIG executive committee regarding the timing of this conference, the duration, topics of interest, invited speakers, and time allotted for open discussion. I would put together the program, working with potential speakers to ensure proposed topics are covered and speakers are prepared and available. The program may include informal sharing between lab groups regarding current projects on pain and IDD research, more formal presentations on key topics of interest (e.g., pain treatment trials, funding opportunities, knowledge translation initiatives, multisite collaborations), and round table discussions. Ideally there would be time for attendees to have individual discussions. As the field of pain in IDD is small, fostering collaboration is an important goal of the PIDDSIG.

#### **Timeline**

As the PIDDSIG is a small group at this time, it would be reasonable to host our inaugural meeting in association with another annual meeting to which many of our members would be traveling to attend. Thus, we would likely host our conference the day or two days before the International Symposium for Pediatric Pain (ISPP) held June 18-24, 2025 in Glasgow, Scotland. This provides ~13 months to prepare for the conference.

#### **Support**

Financial and hands-on support will be necessary to accomplish this goal. Financial support for the conference will be obtained by eliciting sponsors for the event. We have done this recently for our pre-conference workshop for IASP and I would lead this initiative by finding sponsors and reminding the executive committee to seek sponsorships. What is not covered by sponsors will need to be rolled into a registration fee; however, we would aim to keep the fee minimal to encourage attendance at this first conference. I will have assistance throughout the year through my colleagues on the PIDDSIG executive committee as well as my team at Gillette. My team includes four clinical research coordinators, three research assistants, and I have access to a department administrative assistant whom I could ask for minor help as needed.

#### **Outcome and Benefit**

This inaugural PIDDSIG conference has the potential to be a catalyst for a) future biennial meetings, b) new collaborations between scientists, clinicians, and stakeholders, c) generating new scientific ideas, d) reducing bias and beliefs regarding pain and IDD, and e) improving pain management for people with IDD.