

Canadian Post-SSRI/SNRI Sexual Dysfunction Society (PSSD)

2021/2022 Annual Report

We are an association of Canadians who are experiencing, or supporting people who are experiencing, an iatrogenic (meaning caused by a medication or medical treatment) disorder known as Post SSRI/SNRI Sexual Dysfunction (PSSD).

The Society and its associated website are intended to bring together PSSD sufferers and their supporters in Canada and advocate for recognition, research and greater transparency within healthcare concerning the risks of antidepressants.

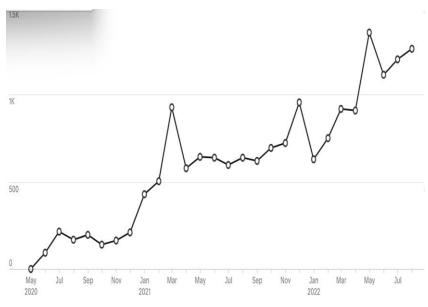
The Society was formally incorporated September 1, 2021, and this is its inaugural report.

The Society is in its infancy and as a result much was done this year to build awareness of its existence, raise awareness of the issue and to offer support to those suffering from this condition. The Society has been successful in developing its presence through multimedia, reaching out and connecting to numerous audiences, individuals, and organizations.



The Society: Its public and organizational awareness:

Members of the Society have made a significant effort over the course of the last year contacting, informing and educating the public as well as medical professionals. A comprehensive website www.pssdcanada.ca has been established, regularly updated, providing



the public, regulating organizations, and professional practitioners with a clear understanding of the condition as well the latest information and research. The most powerful information are personal accounts by those afflicted. Beyond these personal stories the Website provides much information to those suffering from PSSD as well those who are involved in the regulating of the health industry. Since the inception

of this Website the outreach has grown from **50 unique** visits per month to now **1300 unique** site visits per month, a **2,600% increase** – which is significant and provides a forecasting of the magnitude of those afflicted. Further to this between Sept 1, 2021, and August 31st, 2022, the site recorded a total of **14,111** visits.

The Society has established its presence and information dispersal, using Twitter, Facebook and Instagram, REDDIT, podcasts, blog posts and participating in Zoom meetings of health professional organizations.

The Society as part of its commitment to provide support to those negatively affected by SSRIs, responds directly to those making contact through e-mail and has established support groups where sufferers can share common experiences and find strength in community – DISCORD. While the Society specifically declines to provide health related advice or direction, it does offer emotional support, and has worked diligently to provide comprehensive information and listing of resources available as well providing updates on medical research and advocacy efforts.

Significant is the Society's success in having its issues publicized through media outlets, articles published in a national newspaper, the Toronto Star, as well articles in "The Tyee", Visions magazine and an online news magazine "Focus on Victoria". We also had an article published in an online magazine for sexual health practitioners – Sex[m]ed. The Society having direct contact with US FOX news, PSSD issues and the application of SSRI's were discussed on the Tucker Carlson Talk Show. The impact of this discussion that aired on



this talk show is evident in the May 2022 website visits.



Alberta Society for the Promotion of Sexual Health Online Workshop Calendar - September 2021 - June 2022

POST SSRI SEXUAL DYSFUNCTION: LONG-LASTING or PERMANENT SEXUAL DYSFUNCTION AFTER STOPPING ANTI DEPRESSANT TREATMENT #225 Eacilitators: YASSIE DIRANI and EMILY CREY

Facilitators: YASSIE PIRANI and EMILY GREY

February 6-26, 2022



Through the Societies heightened visibility, the society was afforded the opportunity to make presentation in February 2022 via on-line workshop, part of an annual symposium sponsored by the "Alberta Society for the promotion of sexual health". Further to this, the Society made a webinar

presentation to the BC Association of Social Workers. This presentation to the BC Union of Social Workers then provided an opportunity to have partnership with the BC centre for Vulvar health as well publish a PSSD related article in their quarterly magazine.

An exciting development is the inclusion of PSSD as a topic in a Queens University Psychology course syllabus.

The Society: Research and data/information gathering:

The condition of PSSD is heavily under reported and under researched.

The Society, through its outreach, has received significant contact through e-mail from those suffering from PSSD. The Society has developed a membership form and a comprehensive database has been created that will track the number of individuals that have made contact and specifically track the numbers of those who have been negatively affected by the use of SSRI's and SNRI's. This will assist in reporting to institutions and governmental organizations that require quantitative as well qualitative information to encourage and promote action.

The consequences of using SSRI's and SRNI's are considered rare, largely unknown, and unquantified by those in the Health Care industry and those regulating. A focus of the Society this year has been to better understand and quantify the impact of using SSRI and SRNI's. To that end the Society has partnered with Queens University, Sexual Health Research Lab, to support the creation of a directed study/survey to gather important information surrounding PSSD sufferers. This longitudinal survey will be ongoing for 5 years starting in January 2023 and will gather information of PSSD sufferers and inform clinical practice and further research. The Society has advocated this survey with those that make contact.

Following on from the Society encouraging sufferers to be part of the Queens research study, the Society has encouraged these individuals to also make "Adverse drug response reports" to Health Canada.

The Society is also working with an epidemiologist from Simon Fraser University to better understand the prevalence of PSSD. We expect to have preliminary data on the prevalence of PSSD in 2023.

The Society has also built a collaboration with the University of Ottawa, through supporting a Master's student who is writing a thesis on PSSD sufferers and their experience with healthcare providers.

The Society: Advocating and working with Health Canada:

It is the Societies position that there exists a systemic and widespread organizational disbelief/skepticism or intransigence of some negative causal effects that the use of SSRI's and SRNI's can have by health care providers and those regulating. At best dismissive attention is provided to those in need. Further to this it appears that little attention is placed by prescribing physicians or recommending psychiatric specialists on SSRI and SNRI product monograph warnings and risk of side effects; failing to meet an accepted standard for informed consent. As stated by one psychiatric specialist.

"I do not routinely warn my young patients of the possibility of sexual side effects, nor do my child and adolescent colleagues whom I have asked." and,

"I was not aware, nor are the colleagues I have recently asked about this, that there can be long lasting sexual side effects from the use of SSRI medication, even after discontinuation"

The Society has taken an extensive analysis of SSRI and SNRI product safety monographs. From this analysis questions and findings were posed to Health Canada. In one instance where the Society was questioning the lack of clarity around the persistence and ultimately permanence of the PSSD condition, this is the response received.

"Permanence of symptoms can be determined only if patients are regularly and systematically followed-up until death which was not the case for any of the reports. Further, unless evidence indicates that a subgroup of patients have irreversible sexual symptoms based on a complete follow-up until death, such a claim cannot be made",

further to a question regarding Health Canada's interest in further study of this condition, this response was received.

"Because the causal association with SSRIs or SNRIs is uncertain, Health Canada cannot mandate the Industry to run long-term trials to further investigate this issue. As discussed with pharmacoepidemiologic academic experts, observational study designs that may be commissioned by Health Canada cannot be rigorously designed to confidently address this issue." Another question regarding Health Canada's position on using the term Post SSRI/SNRI Sexual Dysfunction or PSSD, this was received.

"This is not yet a DSM-5 or ICD-10 coded term that is universally accepted in the medical community or healthcare systems. DSM-5 is the Diagnostic and Statistical Manual of Mental Disorders used by health care professionals. ICD-10 is the World Health Organization's classification of diseases and recognized medical conditions."

To combat this head in the sand approach taken by Health Canada and healthcare providers, the Society has encouraged and solicited individuals to contact both Federal and Provincial Members of Parliament (MP's) and Legislatures (MLA's), as well send letters of concern to senior Ministers and Health Care providers.

The Society has initiated Freedom of Information requests, seeking documentation regarding the pre-approval process engaged by Health Canada in endorsing the use of SSRI and SNRI's. Specifically, an understanding of the degree of diligence and testing that is exercised prior to drugs being endorsed for use by Health Canada. And further to ensure that risks associated with use of SSRI and SNRI's are clearly stated. While FOI requests have been made, response to these FOI requests has not been timely and in some cases has seemingly been ignored.

The Society has been successful in working with the Member of Parliament from Kelowna – Lake Country to have a Petition tabled in the House of Commons, Canada.

What is obvious is that there is a high degree of reluctance to acknowledge the negative impacts of SSRI and SNRI use. The Societies objective is to remove this reluctance and barrier, to hold governing bodies to account and encourage the health care community and more importantly the regulators to acknowledge the significant negative impacts and to collaboratively work to take reformative action.

The Society: International Collaboration:

The Canadian PSSD Society has promoted numerous international events (webinars, surveys, guest lecturers) that serve to raise awareness and provide information on PSSD. The Society regularly updates its website with events that are occurring around the world, Germany, the UK, Australia, Italy, and the USA. Beyond promotion of these international events, effort has been made to contact and coordinate actions to address the PSSD issue – an international alliance.

The Society: Finances:

The Society has this year established a bank account to receive and disburse funds for society business. The Society, however, has not received any funding through external benefactors or donation and has not expended any society funds. The bank account will be maintained for ongoing business needs. The Society carries a balance of \$0.00 into the next reporting year. Finances to support the hosting of the website and FOI costs have been provided by the Society's directors as a personal donation.

The Society: Acknowledgments:

The Directors of the Canadian PSSD Society would like to offer special thanks and appreciation to those who have been instrumental in advancing the efforts of the Society and supporting the directors in partnership, advice, advocacy, and encouragement of the issue. Without their help, the Society would not have been as effective and influential.

Dr. Caroline Pukall,	Canada Research Chair in Sexual Health, Director Sex and relationship Therapy Service – Psychology Clinic, Queens University
Dr. Amy Pearlman,	Urologist, Sexual Health Specialist,
Dr. David Healy;	Psychiatrist and Psychopharmacologist, McMaster University, Canada
Dr. Peggy Kleinplatz;	Department of Family Medicine, University of Ottawa, Canada
Dr. Melanie Atlas;	Director of the Centre for Vulvar Health, University of B.C.
Dr. Travis Salway;	Epidemiologist, Faculty of Health Sciences, Simon Fraser University
Mr. Johnny Morris,	Chief Executive Officer, Canadian Mental Health Association, British
	Columbia Division.
Mr. Allen Cassels,	Author and Health Policy Researcher, University of Victoria, B.C.
Ms. Moira Wyton,	Freelance reporter, "The Tyee"
Ms. Emily Rice,	Graduate student, University of Ottawa

Respectfully submitted,

Emily Grey