BIOGRAPHICAL SKETCH

March 15th 2021

NAME: **Sylvia Gerda Stockler-Ipsiroglu**	POSITION TITLE: **Professor Pediatrics, UBC; Head, Division of Biochemical Diseases, Dept. of Pediatrics, UBC**

EDUCATION/TRAINING

INSTITUTION AND LOCATION	DEGREE (If applicable)	Completion MM/YY	FIELD OF STUDY
Karl-Franzens University Graz, Austria	MD	3/1983	Medicine
Austrian College of Physicians	Diploma	9/1990	Ped.& Adolescent Med.
Georg-August University Goettingen, Germany	PhD (venia legendi)	1/1996	Pediatrics
Austrian College of Physicians	Diploma	8/1998	Human Genetics (IEM)
Austrian College of Physicians	Diploma	1/2007	Pediatric Neurology
University Economics & Business Affairs, Vienna, Austria	MBA	1/2006	Hospital & Health Care Management
Royal College of Physicians of Canada	FRCPC	9/2009	Pediatrics
Canadian College of Medical Geneticists	FCCMG	11/2018	Medical Genetics

A. Personal Statement

As a pediatrician, neurologist and geneticist my clinical and research interest has been at the interface of holistic and subspecialty-driven pediatric care. As such I have developed main interest in the evaluation of long-term outcomes of treatments for rare inborn errors of metabolism and treatable intellectual disabilities. To that end, I am both principal and co-investigator in several national and international clinical trials and disease registries. Finding personalized therapies through drug repurposing strategies and participation in the first gene therapy trials for inborn errors of metabolism are highlights of my current clinical research activities.

Despite all these advances in academic medicine, there is still considerable inequality in the access to medical care for children with certain socioeconomic and cultural backgrounds, even in highly developed countries such as Canada, US and Europe. Analyzing causes of adherence failures, and developing strategies how to support patients in navigating complex health care systems has been the goal of my past and present activities. As such I have authored several articles on the European viewpoints of Transcultural Pediatrics and I am co-Investigator in a Canadian Research network developing patient-oriented and participatory strategies for the design of clinical trials and outcome studies (www.informrare.ca).

B. Positions and Honors

RESEARCH AND PROFESSIONAL EXPERIENCE

1983-1984	Research Assistant, Dept Lab Medicine, Faculty Medicine (FOM), Univ. Graz, Austria
1984-1989	Resident (Assistenzarzt) Pediatrics & SSR Pediatric Neurology and Clinical Biochemistry, Dept. Pediatrics and Biochemistry, FOM, Univ. Graz, Austria
1989-1992	Clinical Assistant Professor, Dept. Pediatrics, FOM, Univ. Graz, Austria
1993-1995	Clinical Assistant Professor, Dept. Pediatric Neurology, Georg August Univ. Gottingen, Germany
1996-2004	Associate Professor, Dept. Pediatrics, FOM, Univ. Vienna, Austria
1998-2004	Director Austrian Newborn Screening Program, Dept. Pediatrics, AKH, Vienna, Austria
2005-2009	Clinical Professor, Dept. Pediatrics, FOM, University of B.C, Vancouver, Canada.
2005-Present	Head, Div. Biochemical Diseases, Dept. Pediatrics, FOM, University of B.C, Vancouver, Canada.

2005-Present CFRI/BCCHR Researcher, FOM, University of BC, Vancouver, Canada.
2009-Present Professor with Grant Tenure, Department of Pediatrics, University of BC, Vancouver, Canada.

AWARDS

1995 International Horst Bickel Award: Progress in Treatment of IEM
1996 Habilitation prize of the Georg August University of Göttingen
1996 Research Award Austrian Pediatric Society: Best clinical work in 1996 (Lancet 348: 798-90)
1994 Science Award Austrian Pediatric Society: Excellent Clinical Publication: J Pediatr 124: 601-604 (1994)
2002 Clemens von Pirquet Prize for outstanding performance in clinical teaching
2010 Faculty of Medicine Award for Excellence in Mentoring Early Career Faculty, UBC
2010 Molecular Genetics & Metabolism – Top Reviewer 2010
2011 Meritorious Faculty Award, Dept of Pediatrics, UBC
2015 Emanuel Shapira Award for the best publication in Molecular Genetics and Metabolism 2014
2015 UBC, DOP Best Service Award 2014-2015
2016 CORD Rarity Award for Scientific Excellence and Support of the Rare Diseases Patient Community

C. Publications (selected)

http://www.ncbi.nlm.nih.gov/pubmed/?term=stockler+s
http://www.ncbi.nlm.nih.gov/pubmed/?term=stockler-ipsiroglu+s

Evidence rare diseases

Stockler -Ipsiroglu S, Potter B, Yuskiv N, Tingley K, Patterson M, van Karnebeek C. Developments in Evidence Creation for Treatments of Inborn Errors of Metabolism. JIMD First published: 17 September 2020 https://doi.org/10.1002/jimd.12315

Transcultural Pediatrics

Stockler S, Moeslinger D, Herle M, Wimmer B, Ipsiroglu O. Cultural aspects in the management of inborn errors of metabolism. J Inherit Metab Dis 2012 Nov;35(6):1147-52. Feb 23 (Epub ahead of print). Pm 22358739.

Ipsiroglu OS, Herle M, Spoula E, Moslinger D, Wimmer B, Burgard P, Bode H, **Stockler-Ipsiroglu S.** Transcultural pediatrics: compliance and outcome of phenylketonuria patients from families with an immigration background. Wien Klin Wochenschr. 2005 Aug;117(15-16):541-7.

Stöckler-Ipsiroglu S, Herle M, Nennstiel U, Wendel U, Burgard P, Plecko B, Ipsiroglu O. Besonderheiten in der Betreuung von Kindern mit angeborenen Stoffwechselerkrankungen aus Migrantenfamilien Special aspects of the care of children with inborn metabolic diseases from immigrant families. Monatsschrift Kinderheilkunde 2005; 153 (1) 22-28.

Patient-oriented and participatory medicine

Khangura SD, Karaceper MD, Trakadis Y, Mitchell JJ, Chakraborty P, Tingley K, Coyle D, Grosse SD, Kronick JB, Laberge AM, Little J, Prasad C, Sikora L, Siriwardena K, Sparkes R, Speechley KN, **Stockler S**, Wilson BJ, Wilson K, Zayed R, Potter BK; Canadian Inherited Metabolic Diseases Research Network. Scoping review of patient- and family-oriented outcomes and measures for chronic pediatric disease. BMC Pediatr. 2015 Feb 13;15:7. doi: 10.1186/s12887-015-0323-x.

Ipsiroglu OS, Hung YH, Chan F, Ross ML, Veer D, Soo S, Ho G, Berger M, McAllister G, Garn H, Kloesch G, Barbosa AV, **Stockler S**, McKellin W, Vatikiotis-Bateson E. "Diagnosis by behavioral observation" home-videosomnography - a rigorous ethnographic approach to sleep of children with neurodevelopmental conditions. Front Psychiatry. 2015 Mar 17;6:39. doi: 10.3389/fpsyt.2015.00039. eCollection 2015.

Ipsiroglu O, Elbe D, Witmans M, Berger M, Garden J, Loock C, Salmon A, **Stockler S**, Di Pietro N, Carleton B. Challenging/disruptive sleep/wake behaviours in adolescents with fetal alcohol spectrum disorders: Iatrogenic effects of prescription medications. Int J Dev Neurosci. 2015 Dec;47(Pt A):128. doi: 10.1016/j.ijdevneu.2015.04.340. No abstract available.

Ipsiroglu O, Beyazi N, Berger M, Wagner A, Dhalla S, Garden J, **Stockler S**. Emplotted narratives and 'structured behavioral observations' supporting the diagnosis of Willis Ekbom Disease/Restless Legs Syndrome in children with neurodevelopmental conditions. CNS Neuroscience and Therapeutics. CNS Neurosci Ther. 2016 Nov;22(11):894-905. doi: 10.1111/cns.12564. Epub 2016 Jun 13.

D. Research Support (selected)

2011-2016	Collaborative Area of Innovation, B.C.'s Children's Hospital. "Treatable Intellectual Disability Endeavor in B.C. $2.25 million.
2012-2014	CIHR Catalyst Grant: Defining clinically meaningful outcomes for treatment of PKU with Kuvan, $95,000.
2012-2017	The Canadian Inherited Metabolic Disease Research Network (CIHR funded Rare Disease Network. (PI B Potter, P Chakraborty) $1,490,000.
2013-2018	Expanding the number of treatable intellectual disabilities through an integrated –omics approach (CHIR operating grant, PI C van Karnebeek) ($750.000)
2017-2019	Catalyzing registry-based randomized comparative effectiveness trials for inherited metabolic diseases in children: establishing a core outcome set and data collection tools (Potter BK, Clifford T, Pallone N, Stockler S) CIHR Catalyst Grant: SPOR Innovative Clinical Trials $100,000
2020-2024	An innovative registry-based trials platform to improve clinical care, outcomes, and health policy for children with treatable rare diseases" CIHR SPOR Innovative Clinical Trial Multi-Year Grant, CAD 5,508,000; Potter B (Pi) Stockler et al CoPi