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> **Ex-Officio** Lin Fraser, EdD

Student Representative

Luke Allen, MA

EPATH Representative Griet De Cuypere, MD 30 May 2018

RE: RESPONSE TO OPEN LETTER from WPATHopenletter@gmail.com

Dear Open Letter Signers:

The WPATH Board of Directors thanks you for your constructive open letter. We begin by writing that we stand with you. The mission of the WPATH is to promote evidence-based care, education, research, advocacy, public policy, and respect in transgender health. WPATH strives to promote high quality care, in the context of a culture devoted to competent, ethical, and compassionate care. And while we are proud of the progress that has been made, we know there remains much work ahead.

Improving Standards for Medical Care: Training, Certification and Credentialing for Surgeons

We agree that the surgical profession does need to improve the means of determining which professionals are appropriately trained to perform gender-affirming surgical procedures. As part of our effort to encourage the development of competencies in surgical practice, in February 2017, WPATH endorsed a new policy paper directed toward surgeons and surgical societies, "Gender Confirmation Surgery: Guiding Principles" This paper proposes a framework for setting up surgical training programs in gender confirmation procedures and makes recommendations for assessing surgical competency. With several major medical centers in the U.S. now establishing training programs in transgender health, we expect the ability to identify newly trained surgeons who are competent in this subspecialty will improve in the coming years. Furthermore, we encourage individual hospitals worldwide to adapt these guidelines when granting surgeons privileges for performing gender-confirming procedures. We address patient-validated assessment tools on page 5 of this letter.

In addition, to these training programs within hospitals, WPATH has been training providers around the world through our Global Education Initiative (GEI). The GEI is the educational component of a strategic plan developed by the WPATH Board of Directors in

¹ Schechter LS, D'Arpa S, Cohen MN, et al. Gender Confirmation Surgery: Guiding Principles. J Sex Med 2017;14:852-856.



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2013. The GEI trains medical and behavioral health providers to deliver competent care and increases cultural awareness concerning transgender and gender non-conforming (TGNC) people. We provide an overview of the surgical procedures and describe many of the issues faced by TGNC people when We utilize our members around the world to deliver these trainings and every GEI training team includes a gender-diverse group of professionals, including TGNC-identified trainers. After consulting the membership and after many years of exploring how to provide certification, in 2015 WPATH initiated a certification program for healthcare professionals as a member benefit. While our goal is to improve provider competence though education, we also acknowledge that this certification program will not completely resolve the very serious issues mentioned in your open letter.

In principle, we wholeheartedly agree with the establishment of qualifying criteria that must be met by all surgeons performing gender confirmation surgery. However, this ambitious objective presents major challenges. Most notably, there is significant regional, national, and international variation in which a variety of subspecialists perform gender confirmation procedures, making it difficult to identify a single board that would provide certification for surgeons who perform these surgeries. And it is unlikely that one format of training would suit all professionals in every medical system in every culture around the globe.

Board certification is desirable for many medical specialties (see, for example, http://www.abms.org/about-abms/fags-abms/ and https://www.abplasticsurgery.org/about-us/purpose/); however, board certification is not the same as accreditation. While WPATH does unify these different subspecialties within our membership. WPATH is not an accrediting body. In the U.S., accreditation is a voluntary program typically performed by the Joint Commission, a policy body operating under federal regulations that are approved by Congress to promote patient safety, facility cleanliness, and patient-centered communication standards in hospitals and officebased surgery centers. The federal government currently is not particularly amenable to meeting the needs of transgender and non-binary people in the U.S., so we must work within our networks of medical and legal affiliate professionals to shore up the scientific, medical, legal, and mental health protections that we have so far achieved, even as we work to improve our standards and our



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methods of quality control, regardless of the limitations that constrain us.

ACTIONS WPATH TAKES TO PROMOTE QUALITY MEDICAL CARE

While we cannot dictate practice to all people in every country around the globe, we can—and we do—do the following:

- Official Policy Statements. We provide overarching principles and recommendations, such as Public Policy Statements and the WPATH Position Papers, which we submit to governments and policy-making bodies around the world. These position papers and underlying policy statements are available on www.wpath.org.
- Standards of Care. When patients bring complaints against medical providers to the provider's appropriate licensing board, WPATH offers the most widely accepted SOC to support specialized transgender-specific or gender-confirming patient care that is individualized to address unique patient circumstances. Our Standards of Care are updated regularly in response to the changing needs of the TGNC population around the world. We are already in the process of engaging in dialogues with various surgical societies and other medical organizations as we search for ways to improve surgical care and enforce higher standards, and WPATH's interdisciplinary perspective brings a dynamic element into the organizing efforts necessary to adequately respond to transgender health concerns.
- Training. We deliver training and consultation to medical providers around the world. WPATH members have volunteered to train surgeons and support the development of surgical teams to provide increased access to higher quality care on 4 continents so far.
- Publish. We publish research to document surgical techniques and outcomes as well as other issues relevant to transgender health care. The WPATH Journal, *The International Journal of Transgenderism (IJT)*, was the first journal to devote itself entirely to transgender health. Peerreviewed academic journals are historically difficult to access outside of academic institutions, but these are the most respected sources of information that we have with



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which we can reinforce validation of transgender health objectives. IJT articles not only contribute to the medical literature but have been used as authoritative sources in advocacy for TGNC civil rights and access to care.

Creation of a Trans-positive Medical Community. WPATH provides venues and community for surgeons and other specialists, including nurses and social workers. who join WPATH to participate in our activities, and attend our meetings so they may learn from their colleagues and peers, our transgender membership, and from community health care professionals, as well as gain exposure to the WPATH patient-centered philosophy, values, ethical principles, and organizational goals.

COMMUNITY INVOLVEMENT IN SOC 8 AND THE ESTABLISHMENT OF A COMMUNITY ADVISORY COUNCIL

In 2011, The Institute of Medicine (IOM) released "Standards for Developing Trustworthy Clinical Practice Guidelines." These recommendations underscore the need for involvement of consumers and advocates in the guideline development group. To this end we included a stakeholder on each of the chapter teams. Additionally, in accordance with the IOM protocol, there will be opportunity for public comments and feedback on the draft SOC guidelines, where we hope to receive additional community input on the document.

The WPATH Board of Directors agrees that a Community Advisory Council would be most welcome, although the composition and scope of such a Council is still to be worked out. We did have an International Advisory Committee that was very helpful to our writing committee for SOC7, and that committee was recruited from among trans community activists in as many countries as possible to ensure diversity and inclusivity. We are approaching SOC8 with a different methodology (the IOM protocol introduced above).

We understand that the model of 1 stakeholder per chapter in SOC8 does not take the place of a Community Advisory Council. It is also significant that including the designated stakeholders who are TGNC we have at least 43 openly TGNC people on the SOC8 Committee, which increases TGNC perspective considerably as the entire committee develops the content of each chapter. Additional



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EPATH Representative Griet De Cuypere, MD stakeholders are from other constituencies, such as parents of TGNC children, etc.

The process of selecting Committee members for the creation of SOC8 was openly discussed with our membership and was deliberately inclusive. There will be multiple opportunities for WPATH members to have input into the draft document. In addition, the SOC Committee will read all material submitted from constituents outside of the organization.

Like all professional organizations, WPATH must produce Standards of Care based upon systematic evidence review. Validated evidence-based medicine is crucial to the public and governmental (and other institutional) acceptance of genderconfirming treatments. Toward that end we have contracted with an external review board to evaluate the literature which will inform SOC8. This is now standard practice for medical organizations that publish standards of care. To do otherwise would compromise our ability to advocate on behalf of TGNC people in medical and legal settings. The details of this process will be explained in a letter to the membership that the President of WPATH will send out in the coming weeks. The newly formed Community Advisory Council (once it exists) will also play an active role in providing input. The lead authors of the SOC8 will work with the Community Advisory Council to establish the process for their participation.

EVIDENCE-BASED MEDICINE AND THE NEED FOR A RESEACH DATABASE

WPATH acknowledges the need for evidence-based data, and we are committed to moving forward in providing proven and quality care. We agree that a research database specific to the transgender, transsexual, and gender-diverse community is needed. As such, we are in support of several ongoing studies to evaluate individuals' goals, expectations, and satisfaction, as well as short-term and long-term complications and techniques for their mitigation. These various independent studies may not meet all the ideals of the research database proposed in the open letter, which would require a level of cooperation and uniformity across research sites that so far does not exist. The logistics of such a database will be a topic for our work with the future Community Advisory Council.

Our "guiding principles" framework also acknowledges the need for patient-validated assessment tools: "Central to this challenge



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Ex-Officio Lin Fraser, EdD [developing guidelines] is the development of patient-reported outcome measurements (PROM) specific to the transgender and gender-nonconforming population. These measurements must be reliable, valid, and reproducible." However, asking patients to review existing outcome measures is not the same as developing outcome measures with patients. What is important to surgeons is not always the same as what is important to patients. Many of our members have long expressed frustration that surgeons do not track their outcomes beyond immediate surgical recovery. The experience of long-term living with surgical results is different than "good surgical recovery" measured by not having complications in the months post-op. We acknowledge that there is a significant difference between patient-reported outcomes and patient-defined outcomes. Your voices are vital to the development of validated tools and guidelines. This is another issue that has been percolating in the provider community for quite a few years, and we are particularly excited to note that there were over a dozen proposals on the topic of PROM submitted for presentation at our upcoming Symposium in Buenos Aires, which will undoubtedly lead to further discussions and collaborations. We are also aware of several researchers who are developing PROM recommendations, and we welcome their publications as much as we hope they are working with patients to establish what will be the salient questions and their measures. When these PROM recommendations are published, other researchers, providers, and community members will be able to compare the options and weigh in to help create optimal outcome standards.

We hope that signers of the open letter will watch our website for announcements of community input opportunities, stay in touch with colleagues who are active WPATH members to keep abreast of developments within the Association, engage with providers in your geographic areas who are available to participate in local community events, and connect with local, state, and national nonprofit groups that are advocating for transgender health and rights. For those of you who are WPATH members, please join and actively participate in committees that interest you (contact the WPATH office or the committee chair and express your interest and qualifications); this is an effective way to become an influencer within the organization.

Thank you again for your letter. The serious concerns you raised do deserve the full attention of the professional community. We have



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tried to address to the best of our ability each point you have raised. We know there is significant effort ahead; we have been working toward these goals for many years, and we are excited to build more effective partnerships with non-member organizations and constituent groups. All Board Members, Officers, GEI trainers, and all Committee members in WPATH volunteer their time to the organization because we care deeply about the field of transgender health. We look forward to working together to continue improving the lives of transgender and gender-nonconforming individuals though access to quality medical care. Working together is the most powerful way to have an impact on the vast mechanism that controls health care service distribution, access, and costs in the U.S. and around the world.

Sincerely,

Gail Knudson, MD, FRCPC

WPATH President, on behalf of the WPATH Board of Directors:

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