



International WAGR Syndrome Association Medical and Scientific Advisory Board Policy

Adopted April 2018

Purpose

The purpose of the International WAGR Syndrome Association (IWSA) Medical and Scientific Advisory Board (MASB) is to

provide oversight, advice, and expertise regarding key medical and clinical issues for the conditions associated with WAGR syndrome. The MASB promotes new developments in diagnosis, treatment, care, and medical research on a global level, and guides the IWSA's research activities.

The MASB is composed of leaders in WAGR syndrome research and clinical practice who have made significant contributions to advancing their respective fields and are committed to furthering IWSA's mission of eliminating the challenges of WAGR syndrome through research, awareness, and support.

Structure

Composition: Members of the MASB will represent the various research and clinical specialties that are encompassed by the many facets of WAGR syndrome including, but not limited to -- ophthalmology, genetics, hematology/oncology, endocrinology, psychology, and nephrology. The composition of the MASB also will reflect the international character of IWSA. The MASB will consist of 6-16 members, who have been invited to serve by the Board of Directors of the International WAGR Syndrome Association.

Eligibility: Members of the MASB must be willing to support and assist with the mission, goals, objectives and values of International WAGR Syndrome Association. Individuals should be professionals with accomplishments that can be documented by

reputation, publication, and/or direct experience with and knowledge of WAGR syndrome.

Terms: MASB members will serve for terms of three (3) years. At the end of his/her term, a MASB member may be invited to serve for another term, with no limit to the number of consecutive terms permitted, though rotation of membership is expected. A member of the MASB may resign by submitting a written notice to the International WAGR Syndrome Association Board of Directors. At any regular meeting or special meeting called for this purpose, the International WAGR Syndrome Association Board of Directors may fill a vacancy on the MASB by electing a new member.

Compensation: Members of the MASB will receive no compensation for their time or their expertise. MASB members will be reimbursed, however, for expenses that are incurred in order to fulfill their specific responsibilities to International WAGR Syndrome Association, as long as these expenses are reasonable and appropriate, are authorized ahead of time, and are not covered by other means.

Roles and Responsibilities

Members of the Scientific Advisory Board are expected to be active participants in and advocates for the International WAGR Syndrome Association. Members may be asked to assist IWSA in a variety of ways, depending on their interests and abilities as well as the needs of International WAGR Syndrome Association. Not all of these duties will fall to any one individual, but the types of responsibilities one should expect might include, but are not limited to:

Making recommendations to the IWSA Board of Directors concerning the development and execution of appropriate and effective research strategies to encourage research funded by third parties and to establish guidelines, solicitation, approval and oversight processes for International WAGR Syndrome Association-funded grants.

Ensuring that other members of the MASB and the IWSA Board of Directors are kept abreast of research and clinical work that is being done in fields relevant to WAGR syndrome and keeping them informed about promising areas of basic, translational science as well as clinical research.

Contribute to an Annual Report for the IWSA Board of Directors that will encompass the following: Need for new written materials and/or policy statements, research and technology approach updates, updates in genetic testing technologies, and/or new developments in clinical care.

Evaluating the significance and meaning of published research papers relevant to WAGR syndrome and sharing this with International WAGR Syndrome Association.

Provide guidance on drug development process and what's required to move from basic research to human clinical trial.

Writing, editing or reviewing printed material to be approved and distributed by International WAGR Syndrome Association.

Participating in WAGR Weekend, the annual family gathering of the International WAGR Syndrome Association.

Helping to improve both the quality and quantity of data in the International WAGR Syndrome Association WAGR Patient Registry, consisting of data furnished by WAGR syndrome patients and their families for use by approved researchers and clinicians dealing with WAGR syndrome.

Providing guidance and support to International WAGR Syndrome Association in the creation and execution of targeted awareness programs directed toward various segments of the medical and scientific communities.

Serving as spokespersons for International WAGR Syndrome Association at professional conferences, in the media, and at certain fundraising events.

Assisting International WAGR Syndrome Association with contacts at a variety of medical and scientific institutions and organizations.

Responding to clinical and research inquiries from the various International WAGR Syndrome Association constituencies: patients, families, physicians, researchers.

Offering assistance in International WAGR Syndrome Association's desire to provide access to specialized diagnostic and treatment resources in order to create and deliver successful diagnoses, treatments.

Allowing his/her name to be displayed as a member of the International WAGR Syndrome Association's Medical and Scientific Advisory Board on IWSA letterhead, in various IWSA publications and on the IWSA website: <http://www.wagr.org>

In carrying out these duties, each member of the MASB will be responsible for keeping certain information about IWSA, researchers, grants, and individual patients confidential, as dictated by regulation (e.g., HIPAA), or high medical ethics standards, or as requested by International WAGR Syndrome Association.



Dear Dr. _____,

We would like to invite you to join the Medical and Scientific Advisory Board of the International WAGR Syndrome Association. This board consists of leaders in research and clinical practice who have made significant contributions to advancing their respective fields and are committed to furthering the International WAGR Syndrome Association's mission to promote awareness, stimulate research, and to support families affected by WAGR syndrome.

The responsibilities of our Medical and Scientific Advisory Board members are to:

- Enable the IWSA to identify, support, and understand research for WAGR syndrome
- Advise on the implementation or pursuit of any scientifically credible approach to therapeutics
- Define and administer IWSA's research grant program, including RFP development, proposal review and grant oversight
- Promote collaboration in the WAGR syndrome research community
- Provide speakers for WAGR Weekend, the annual family gathering of the IWSA

We admire the work you have done with respect to WAGR syndrome and related disorders, and we would be very grateful to have your insight and expertise as we go forward.

Sincerely,

Shari Krantz
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