

INTERNAL RULES

WORKING GROUP ON RARE AND INHERITED KIDNEY DISORDERS

Working group of the Swiss Society of Nephrology
(unanimously approved at the SGN Board meeting of 16.12.2020)

Description of the Working group

Working group on rare and inherited kidney disorders - WGRIKD

Preamble

Each working group prepares internal rules, which must be submitted to the SSN Board for approval.
Each working group works under the responsibility of the SSN

Aim / mission of the working group

The **Working Group on Rare and Inherited Kidney Disorders of the Swiss Society of Nephrology** aims are:

- to **encourage communication and disseminate knowledge**, in whole Switzerland, on the clinical, genetic, mechanistic and social aspects of inherited and rare diseases affecting the kidney;
- to **foster exchange** between adult and pediatric nephrologists, geneticists and researchers, actors involved in ethics, health economics, etc...;
- to **organize specific meetings**, with priority for **case discussion** and organization in the various regions of Switzerland.
- to **address the need for epidemiology data and registries**, the necessity for earlier and more efficient **diagnosis**, as well as **improved and affordable care**;
- to **share experience** with health care providers, patients and their families;
- to contribute actively to the **Concept on Rare Diseases** of the BAG

Definition of the interaction

The working group reports to the SSN Board;

Structure of the working group (chair, vice-chair, number of members)

- The Working Group consists of a President, vice-president, secretary and members.
- the WG elects out of it's members a Vice-President and a secretary, which build, together with the president and an SSN liaison member, the Executive Office of the WG. Together, they are responsible for preparing the annual working plan, which must be approved by the WG.

CHAIR

The Working Group is directed by the President, assisted by a Vice-President.

SECRETARY

The President proposes the name of the Secretary, who is elected by the WG members. The Secretary will be in charge of the organizational affairs of the Working Group. In particular, he organizes meetings of the WG in close collaboration with the other Executive Officers. He must inform all members about the venue and time of the meeting at least one month before.

The Secretary will prepare Minutes of the meetings, which must be approved by the Executive office and sent to members and to the SSN office.

The Secretary is the person responsible for ensuring that these regulations are followed by the WG.

MEMBERS

WG members are persons interested in inherited and rare kidney disorders at large. Submission for WG membership should be addressed to the Secretary of the WG. WGIRKD members should be members of the SSN, but exception may apply to representatives of the geneticist's community and basic researchers.

Current member list - see www.swissnephrology.ch

Election mode of the working group members

- The President is proposed by the WG Executive Office to the SSN General Assembly for a 2 year office term and can be re-elected twice. The proposition has to arrive until latest end of April in the election year at the SSN office.
 - The board can inform SSN members about a vacancy of Presidency until 1 of June in the election year. SSN members can apply for the vacant post until latest 30th of Sept in the election year. Qualified candidates can then be submitted for election to the General Assembly of SSN.
- The Vice-Chairman represents the adult/pediatric nephrology counterpart of the Chairman, to ensure optimal representativity.
- Members of the WG are elected by the Executive Office and members.
- Candidates for membership must send their application to the WG Secretary until latest 30th of Sept in the election year. The Secretary will be in charge of verifying the eligibility of the candidates and informing the Executive Office and the members. Internal vote might be conducted by email and is organized by the Secretary.
- Notice of any Board vacancy must be sent to all WG members until latest 1st of June in the election year by the WG Secretary.

Length of mandate

President: 2 years. Re-electable twice.

Members: not limited

Number of working group members

No limitation

Internal vote modalities

During elections/voting, in case of an equal number of votes, the Chairman has the casting vote. For a valid decision, 50% of the members have to present.

Number of meetings per year

At least one meeting is organized (spring) for case discussions, plus one during the SSN Annual meeting.

Minutes of meetings

14 days for writing and 14 days for approval.

Should reach the SSN Board within max. 30 days after meeting.

Diffusion of information of the working group publications by the working groups

All publications and notifications are to be submitted to the SSN Board before publication.

Commission decisions and recommendations are open to all SSN members (website or mailings)

Mandatory yearly report to GA

Each working group will submit an annual report to the ordinary SSN General Assembly.

To be submitted to the SSN Office in writing by each end of September

Admission as working group or dissolution

The General Assembly of the SSN decides about admission or dissolution of the working group

Distribution of communications

All SSN communications are after consultation with the SSN president or secretary, exclusively sent via the Administration

Financial aspects

The commission has no financial interests. The president and its members have to declare possible personal financial interests and dependencies before taking office and anytime such interests appear. Declaration in a written form to the SSN office. Projects and Coworking with companies (Pharmaceutical, Med-Tech) have to be adherent to the specific rules of FMH.