

ADVOCACY IN INTERNATIONAL ORGANIZATIONS

Wolfgang Grisold and Walter Struhal

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Prof. Dr. Wolfgang Grisold,
Ludwig Boltzmann Institute for Experimental und Clinical Traumatology
Donaueschingenstraße 13
A-1200 Vienna, Austria.
wolfgang.grisold@wfneurology.org

Prim. Assoc.Prof. PD Dr. Walter Struhal, FEAN
Chair, Department for Neurology, University Clinic Tulln, Karl Landsteiner University of Health
Sciences
•Chair, WFN e-Communications Committee
World Federation of Neurology
www.wfneurology.org

COI

- No COI in relation to the topic of this lecture.

- **Learning Objective:**
- To familiarize with advocacy, describe several models of advocacy,
- **Key message:**
- Advocate for neurology !

Advocacy

....is (1) *about* something, that is, in the most general sense, the well-being of the patient, (2) done *by* an advocate, and (3) *on behalf* the patient.

Advocacy activities must build on the *uniqueness, or individuality* of the patient.

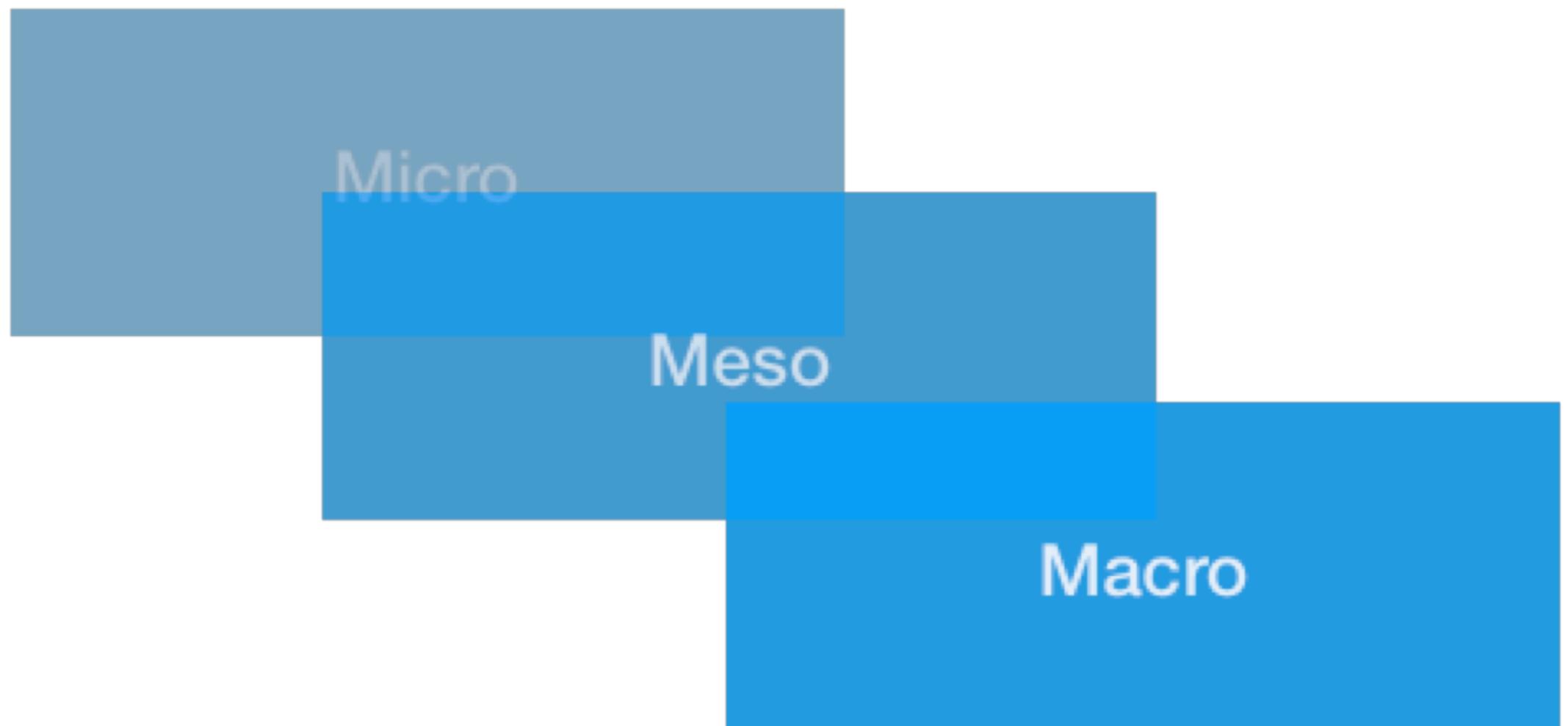
Advocacy

„Knowledge and science is not enough“

Defining terms

- What is advocacy ?
 - „The advocate“
 - Advocate and advocatee
 - Self advocacy
 - Advocating for others
- Levels: Micro-Meso-Macro

- Levels of advocacy:



Example: On the Hill

Francis S. Collins,
MD, PhD

Richard S. Finkel,
MD

Talile Z. Baram,
MD, PhD

Lisa M. DeAngelis,
MD, FAAN

UNIVERSITY OF CALIFORNIA-IRVINE, IRVINE, CA
How Early-life Experiences Sculpt Your Brain:
From Molecules to Circuits



April 21 – April 27 • Los Angeles

Sidney Carter Award in Child Neurology

Richard S. Finkel, MD
Nemours Children's Hospital, Orlando, FL
Spinal Muscular Atrophy Is a Treatable
Neurodegenerative Disease

Robert Wartenberg Lecture

Lisa M. DeAngelis, MD, FAAN
Memorial Sloan Kettering Cancer Center,
New York, NY •

New Career Essentials Conference Helps Lay Foundation for Success

A new AAN conference, Career Essentials: Foundation for Your Future, is set to take place January 13 and 15, 2018, at the Caribe Royale Orlando in Florida. It is offered concurrently with the popular Breakthroughs in Neurology Conference.

Designed specifically for neurologists in private practice and academia who are no more than five years post-residency,

Career Essentials

Stand up for Neurology! Apply for the 2018 Neurology on the Hill

Health care reform continues to influence our work as neurologists and the lives of our patients. Join your AAN colleagues at Neurology on the Hill from February 26 to 27, 2018, and help educate members of Congress so we can address critical health policy problems together. If selected, you will receive training to bring you up-to-date on key issues. Then, we will go to Capitol Hill for face-to-face meetings with congressional members and

THIS ISSUE

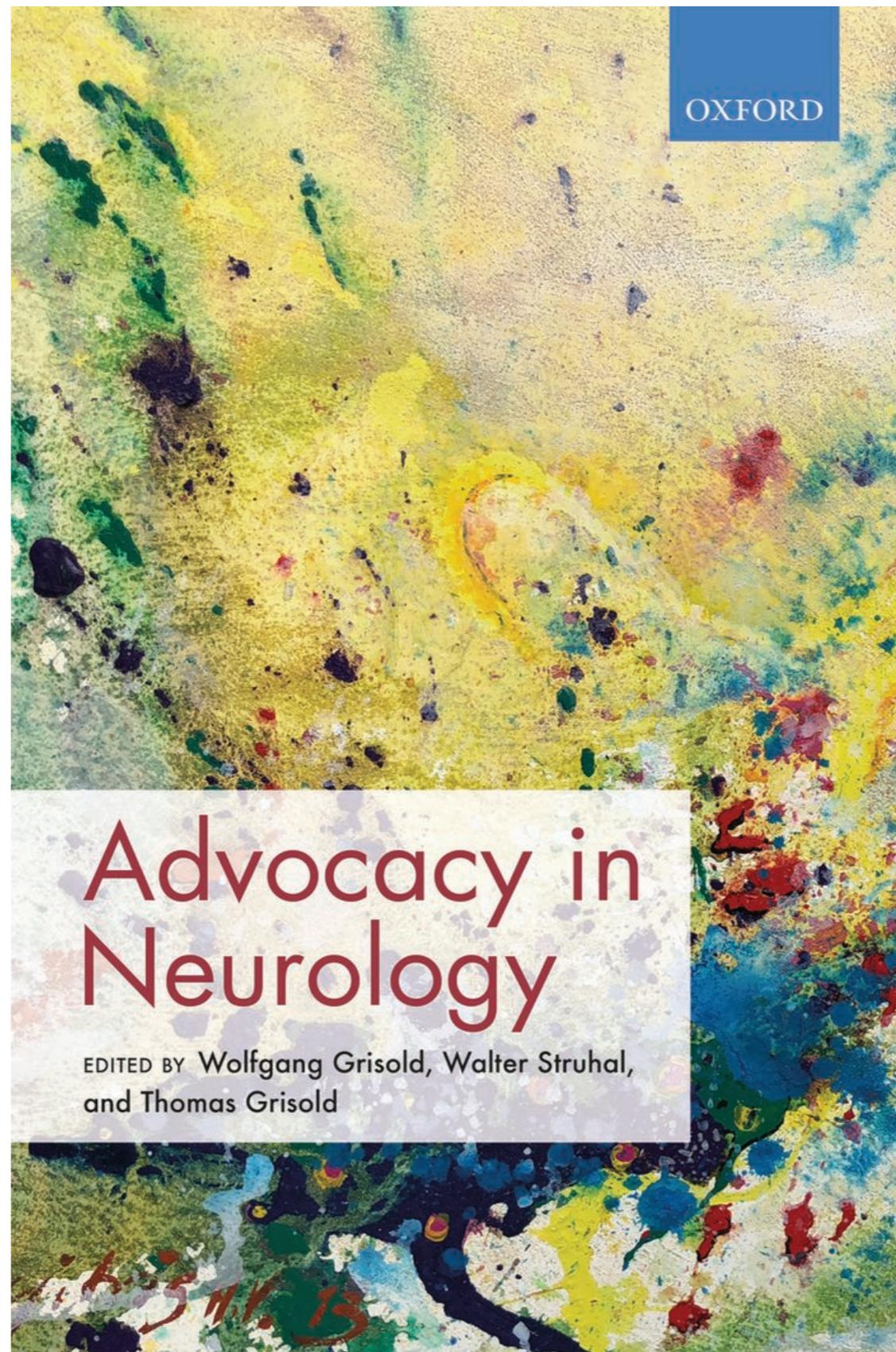
- 8 Submit Your Best Science by October 23 Deadline
- 10 Apply by October 25 for Prestigious 2018 AAN Scientific Awards
- 18 Learn How to Make Technology Work for You
- 19 Use the Axon Registry to Prepare for MIPS

Aims and goals

- Patients
- Target- and goal
- „Things“ - circumstances
- Causes
- Procedures
- Therapies
- Laws/Jurisdiction

Culture

- Culture
- Culture in organisations
- „Political thinking“
- Teamwork and synergy



Several chapters are quoted in this slide series.
The book is available in parts in „google books“
as a „preread“.

Organisations

- SOS Children's Villages
- ECCO Cancer „specific care“
- Neurological subspecialities

SOS

SOS Children's Villages

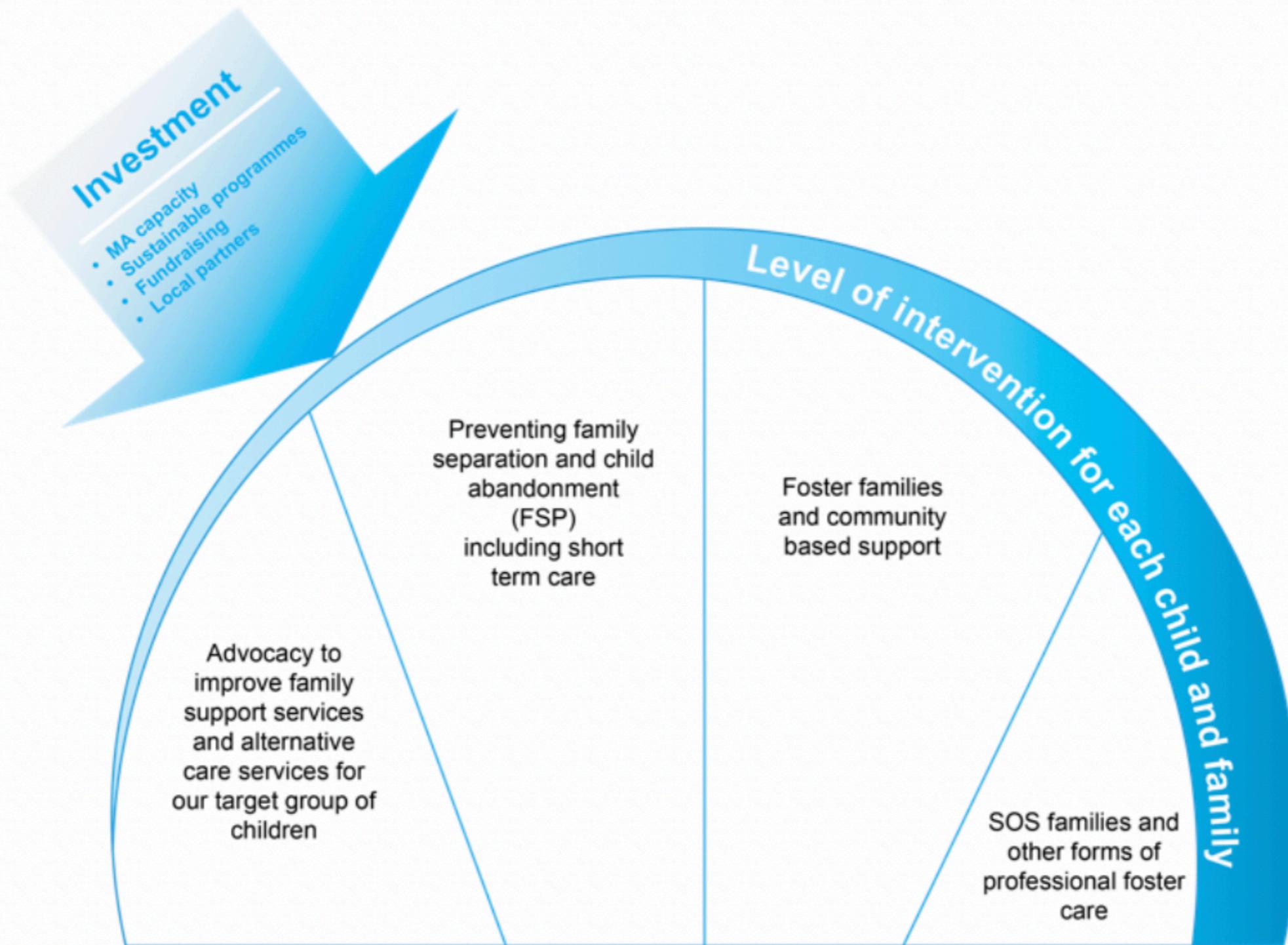
Re-discovering Advocacy to increase relevance and impact. A high level case study

SOS Children's Village had engaged in advocacy in the very early days (1950s) but began to focus on service provision and largely disconnecting it from the professional discourse.

By the late 1990s the organisation expanded into over 100 countries. Despite doing excellent work as service provider, the organization felt the threat of being of little relevance, losing support and recognition.

The organization had to re-discover how to engage in advocacy as integral part of its mission. Missing elements in the UN Convention on the rights of the Child offered the chance to convince internal and external public of the need of SOS Children's Villages to engage in advocacy.

Advocacy



Strategic goals

STRATEGIC GOALS

- 1 We ensure that many more children have a loving home and an equal chance to succeed in life, by strengthening the quality and outreach of our programmes
- 2 We drive a global care movement, uniting people and partners, so that 'no child should grow up alone'



OUR TARGET GROUP

Children without parental care or at risk of losing it who live in extremely disadvantaged circumstances (220 million children worldwide)

7 STRATEGIC INITIATIVES (SI)

to support our target group and reach our goals:



ECCO

Françoise Van Hemelryck

Patient involvement in European cancer societies – the example of ECCO - the European CanCer Organisation (<https://www.ecco-org.eu>)

ECCO

Patient Advocacy Groups in Oncology

Representatives of the following patient advocacy organizations are members of the ECCO Patient Advisory Committee (2016-2018).

Examples:

International Brain Tumour Alliance (IBTA) (www.theibta.org)

Myeloma Patients Europe (MPE) (www.mpeurope.org)

Leukemia Patient Advocates Foundation (www.cmladvocates.net)

EuropaColon and Global Colon Cancer Alliance (www.europacoln.com)

European Men's Health Forum (EMHF) (www.emhf.org)

ECCO 2015

- Good communication is a central component of clinical care .
- Genetic testing may reveal inherited mutations, and is giving rise to new ethical considerations.
- Patients should demand reliable biobanking.
- Biosimilar medicines can increase access to effective biologics.
- Children have rehabilitation needs specific to their age after cancer treatment.
- There is a need for official European protocols for best practice by employers .
- Multidisciplinary teams are the cornerstone of good care. One of the main challenges now is how to include patients and GPs in multidisciplinary teams.
- Clinical trials are a significant burden to patients. Patients in clinical trials may have a wholly negative experience. The process could be improved and patients' input from the early stages of trial conception, including in IRB discussions and grant panels, will help. Ultimately, randomised trials protect patients against beliefs that have taken hold in the medical community.

Neurologic and other specialities

- Stroke
- European MS platform
- ALS
- Neuromuscular
- Movement
- Brain tumors
- Dementia
- Orphan diseases in neurology
- Palliative Care
- Epilepsy
- Headache
- Neuropathic Pain

Example: MS



[Sylvia Lawry](#) (nee: Friedman; born in [Brooklyn](#), New York, June 28, 1915) was a social campaigner on behalf of people with [multiple sclerosis](#). She founded the [National Multiple Sclerosis Society](#) (United States) in 1947 and co-founded the [Multiple Sclerosis International Federation](#) in the same year.

Patient Advocacy for MS



Two decades of patient advocacy in Multiple Sclerosis the success story of the “European MS Platform”

Comparison of different advocacy projects

- The contents and targets need to be „tailored“. The procedure is similar and ranges from project development, towards implementation, project management, finalization, debriefing and results.

Teaching advocacy

- Teaching advocacy is important and is essential for the work of neurologist.
- The American Academy of Neurology, has established a Palatucci course concept, which teaches the essentials of advocacy.
- The WFN holds regular Advocacy Palatucci courses at the WFN World congresses

Teaching Advocacy

- Project management
 - Advocacy goals
 - Organization and Team work
 - Motivation
 - Avoid procrastination
-
- Goals and milestones
 - SMART
 - Sound bite
 - Elevator message

Advocacy planning



- Project definition
- Project management
- Project team
- Communication



- Project management
- Project duration



- Project ending
- Project team debriefing
- Results

Take away

- Knowledge and science is not enough.
- Everything is politics.
- Being a trained advocate any neurologist can achieve more for patients.

Closing remarks

- Advocacy is not a remote activity, but part of the daily work of a neurologists.
- Advocacy can be useful at several levels.
- Advocacy is practiced in many organizations, and also neurological subspecialties have interesting advocacy models.
- Advocacy can be trained and taught.

References

Advocacy in Neurology

Edited by Wolfgang Grisold, Walter Struhal, and Thomas Grisold

Oxford University Press, 2019

(several chapters were quoted from this book)

Advocacy Skills for Health and Social Care Professionals

Neil Bateman.

Jessica Kingsley Publishers

London and Philadelphia 1995

Association WM. Medical Ethics Manual. © 2005 by The World Medical Association, Inc.

Guerilla advocacy: using aggressive marketing techniques for health policy change. Health promotion practice. 2009;10:325-7.

Wasay M, Hauth E Advocacy training in neurology: scope and impact. Nat Clin Pract Neurol. 2008 Feb; 4(2):114-5.