

Developing Needs-Driven Medical Education For Healthcare Professionals in Myasthenia Gravis

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Conflicts of interest

James F. Howard Jr. has received research support (paid to his institution) from Ad Scientiam, Alexion AstraZeneca Rare Disease, argenx, Cartesian Therapeutics, the Centers for Disease Control and Prevention (Atlanta, GA, USA), the Myasthenia Gravis Foundation of America, the Muscular Dystrophy Association, the National Institutes of Health (including the National Institute of Neurological Disorders and Stroke and the National Institute of Arthritis and Musculoskeletal and Skin Diseases), PCORI and UCB Pharma; has received honoraria/consulting fees from AcademicCME, Alexion AstraZeneca Rare Disease, Amgen, argenx, Biohaven Ltd, Biologix Pharma, CheckRare CME, F. Hoffmann-La Roche, Medscape CME, Merck EMD Serono, NMD Pharma, Novartis, PeerView CME, Physicians' Education Resource (PER) CME, PlatformQ CME, UCB Pharma, Regeneron Pharmaceuticals, Sanofi US and Zai Labs; and has received non-financial support from Alexion AstraZeneca Rare Disease, argenx, Biohaven Ltd, Toleranzia AB and UCB Pharma.

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Nicholas J. Silvestri is a consultant/advisor for argenx, Alexion, Amgen, Annexon Biosciences, UCB Pharma, Immunovant and Janssen; speaker for argenx, Alexion, UCB Pharma and Takeda.

Kimiaki Utsugisawa has served as a paid Consultant for argenx, Chugai Pharmaceutical, HanAll Biopharma, Janssen Pharmaceuticals (now Johnson & Johnson Innovative Medicine), Merck, Mitsubishi Tanabe Pharma, UCB Pharma and Viela Bio (now Amgen); and he has received speaker honoraria from Alexion Pharmaceuticals, argenx, the Japan Blood Products Organization and UCB Pharma.

Heinz Wiendl is a Scientific Advisor for AbbVie, Alexion Pharmaceuticals, argenx, Bristol Myers Squibb/Celgene, Janssen, Merck, Novartis and Sandoz. He has received speaker honoraria and travel support from Alexion Pharmaceuticals, Biogen, Bristol Myers Squibb, Genzyme, Merck, Neurodiem, Novartis, Ology, Roche, TEVA and WebMD Global and is a paid Consultant for AbbVie, Actelion, argenx, BD, Biogen, Bristol Myers Squibb, EMD Serono, Fondazione Cariplo, Gossamer Bio, Idorsia, Immunic, Immunovant, Janssen Pharmaceuticals, Lundbeck, Merck, NexGen, Novartis, PSI CRO, Roche, Sanofi, the Swiss Multiple Sclerosis Society, UCB Pharma and Worldwide Clinical Trials. His research is funded by the German Ministry for Education and Research, Deutsche Forschungsgesellschaft, Deutsche Myasthenie Gesellschaft e.V., Alexion Pharmaceuticals, Amicus Therapeutics Inc., argenx, Biogen, CSL Behring, F. Hoffmann-La Roche, Genzyme, Merck KgaA, Novartis, Roche and UCB Pharma.

Sophie Barry and **Michelle Mackechnie** are employees of UCB Pharma.

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Defining the problem in 2020: An evolving MG treatment landscape and a lack of robustly designed ongoing education for the MG medical community



Literature search (2009–2019):

Little existing research on learning needs and professional practice gaps in MG



Analysis of existing MG and neurology educational provision:

Lack of needs-driven, outcome-focused education



Learning needs assessment:

Key areas of unmet learning need for neuromuscular experts and neurologists

The rarity of patients is mirrored by the scarcity of clinical experts who are spread around the globe; a forum to connect MG experts to learn from and share experience was lacking

Objective:

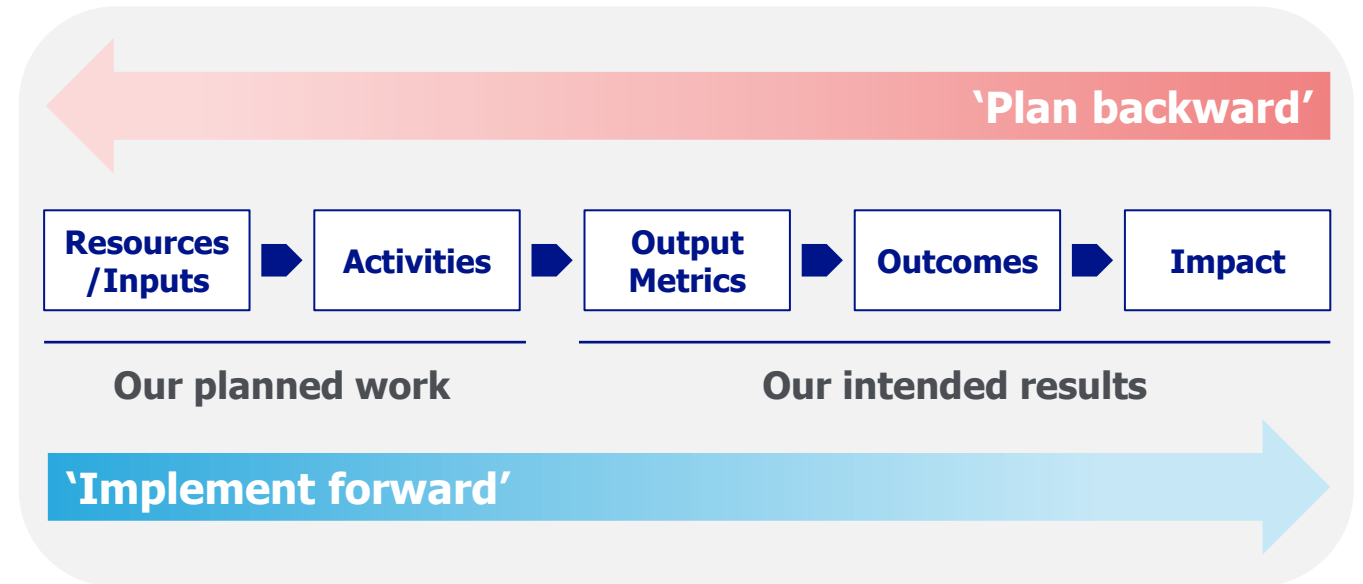
To cultivate an international MG community and provide a forum for knowledge translation, providing needs-based, outcome-focused learning

Defining the solution: The educational program was developed using backward planning

Logic models are **recommended in medical education literature** to describe learning curriculums and evaluate their success

A **logic model** leveraging **backward planning**, a foundational principle of robust learning, was used to design the educational program

- Results were defined upfront with **evaluation against the defined metrics** integrated into the program



10-year ambition:
Offer 'lifelong transformational learning' and cultivate a global MG community of practice, to improve the lives of people and families living with MG

Shaped by the MG community, for the MG community

An international Steering Committee defined the focus of the Rare Disease Connect in Neurology program

- Years 1–2 to focus on neuromuscular experts and neurologists with MG interest
- Year 3 and beyond to include MDTs and offer interprofessional education

Touchpoints across the first 24 months and meeting content were planned based on the pre-defined outcomes covering:

- Immunology of MG and MG pathophysiology
- Patients' disease burden
- MG classification
- Challenging patient populations
- Interprofessional collaboration
- Innovation in MG

International Steering Committee



Prof. James
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USA



Dr. Renato
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Italy



Dr. Pushpa
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Prof. Nicholas
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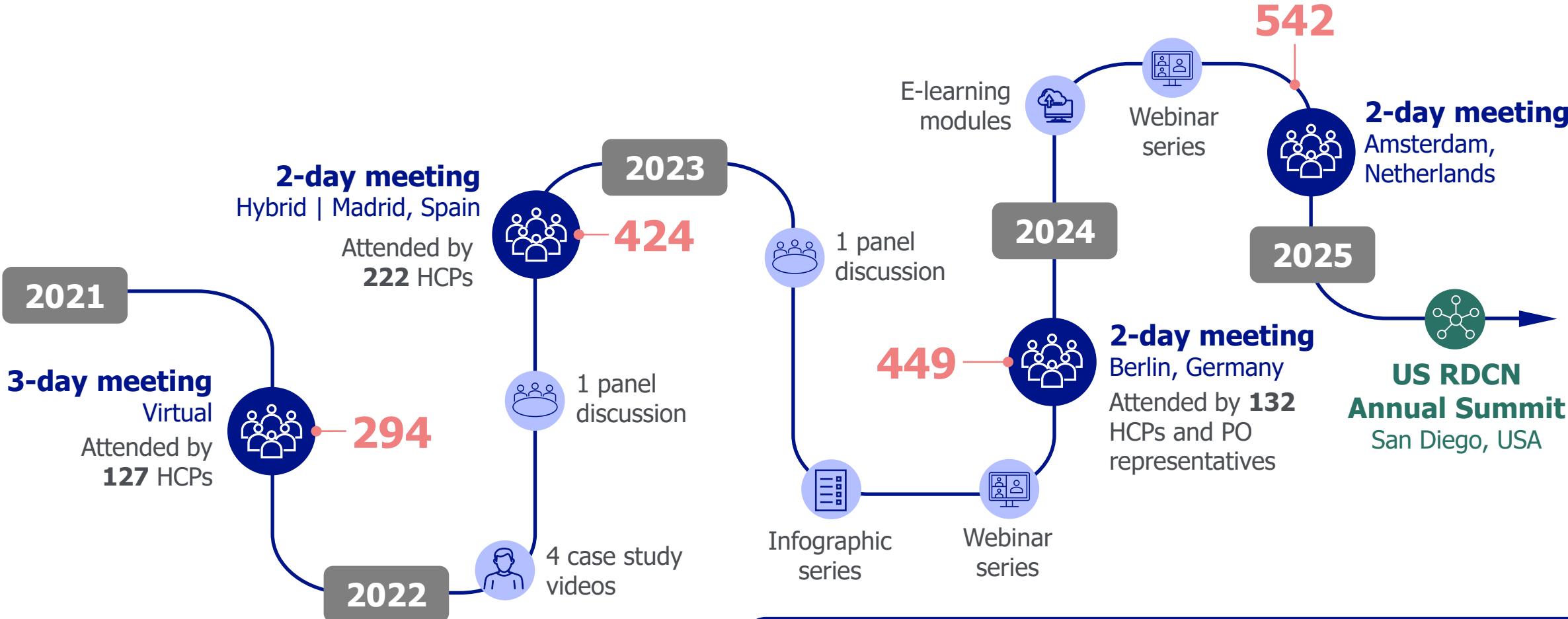


Dr. Kimiaki
Utsugisawa
Japan



Prof. Heinz
Wiendl
Germany

A growing international MG community



X Registered members of the online community

As of 2024, this virtual HCP community has expanded by 70% since 2021

HCP, healthcare professional; MG, myasthenia gravis; PO, patient organization.

Achieving consistent success per pre-defined metrics

“ ... an **unprecedented activity** in the field of MG... ”
2021



2022, 2023*

“Overall, based on the annual meeting, I will come back next year”
>75% participants state intention to return



2021, 2022, 2023

“I would recommend the educational program to my peers”
NPS \geq 50 'excellent'



2021, 2022, 2023

“The educational program improved my knowledge”
HCP impact score \geq 7 'valuable'

Feedback indicated that this program is providing invaluable medical education and engagement

*Intention to return not assessed in 2021.

HCP, healthcare professional; MG, myasthenia gravis; NPS, net promoter score.

Summary: This program supports robust education in MG



Following a learning needs assessment, a **product-agnostic educational program**, Rare Disease Connect in Neurology, was initiated in 2021 – **shaped by the MG community, for the MG community** – using **robust educational design principles**



542 HCPs are now part of this global virtual community designed to provide evidence-based education with the goal of **improving outcomes for patients living with MG**



The program, providing **invaluable medical education**, is being expanded to offer **interprofessional education** to multidisciplinary team members and to create **regional meetings** in USA and Japan