Roundtable on Vitiligo



Background

The Roundtable on Vitiligo will be hosted by the non-profit VR Foundation, firmly committed to expediting vitiligo research and end of suffering for those affected by this neglected disease. The project builds on the World Vitiligo Symposium (2011) and the World Vitiligo Day (2012) initiatives. An early priority for the VRF was to establish the agenda of three specific panels, that is, which topics and issues should receive priority attention and thus have resources allocated towards a solution.

Date: December 14, 2012 **Venue**: Winter Consensus Conference of the World Health Academy (Switzerland) **Place**: Hotel Kempinsky, Kitzbühel, Austira

Purpose

To gather public, industry, and subject matter expert input that will help in understanding disease pathogenesis, development of novel therapies and raising global awareness for the benefit of the underserved patient group.

Format

The Roundtable on Vitiligo includes three Task Forces, comprised of academic researchers, biopharma executives, practitioners, and representatives of public advocacy organizations. We are exceptionally honored by the participation of Nobel Prize winner, who will address different aspects of modern science, society and industry.

- The Global Awareness Task Force will focus on the World Vitiligo Day 2013 media and public campaign.
- The Life Science Task Force session is an invite-only, unbiased discussion of the challenging research topics and promising therapies.
- The CEO Roundtable Task Force session is an invite-only meeting of the CEOs of the biotechnology and pharmaceutical companies involved in vitiligo product development.

Opening Discussion (8.30 – 10.00 on December 14, 2012)

During our opening "Go Round," we will discuss what is new in vitiligo R&D and what it means to you, and how your healthcare or patient support organization may respond to it.

Chairperson: Prof. Torello Lotti.

Co-Chairs: Prof. Robert Schwartz; Prof. Charles Townes.

Presenters include (TBC):

- Prof. Torello Lotti; "Vitiligo: What's True, What's Not."
- Prof. Robert Schwartz; "Vitiligo: Illuminating Prospects."
- Prof. Charles Townes, Nobel Prize and Templeton Prize Winner; "Meeting of Science and Religion in Modern Times."
- Mr. Yan Valle; "At the Crossroads of Science and Industry: an Interdisciplinary Approach to R&D."
- Dr. Igor Korobko; "Golden Standard in Biobanking for Vitiligo and Rare Diseases."

Global Awareness Task Force (10.30 – 12.00 on December 14, 2012)

With approximately 100 million people in the world affected by vitiligo, this annoying pigmentary disorder touches every strata of the population, and every sector of the economy. Further, the person with vitiligo shares its effects with his or her family and, to a different degree, society in general.

The intent of this Task Force is to understand the challenges vitiligo patients and practitioners face in various social or health care settings and to build an effective public awareness campaign.

The objective of the Global Awareness Task Force is to coordinate the World Vitiligo Day campaign and related media activities in the year 2013. The VRF will provide participants with the updated media kit.

Chairperson: Mr. Lee Thomas, an award-winning Fox TV anchor presenter in his hometown Detroit and an international speaker for vitiligo.

Co-Chairs: Ms. Ogo Maduewesi, CEO VITSAF (Nigeria); Mr. Yan Valle, CEO VR Foundation (USA).

Life Sciences Task Force (14.00 – 18.00 on December 14, 2012)

The Life Sciences Task Force is be composed of eminent senior researchers and key opinion leaders from such diverse backgrounds as biochemistry, dermatology, genetics, molecular biology, immunology and oncology.

The intent of this Task Force is to stimulate unbiased scientific discussion, ultimately leading to the creation of balanced and sensible Vitiligo Map. Each of the participants will briefly present his or her vision of vitiligo pathogenesis or cellular/molecular processes affected in vitiligo, and provisional key targets for treatment.

The objective of this session is to pinpoint the most promising research directions, possible leads and hypothetical treatments.

Presenters (TBC):

- Dr. John Harris; "Immune system in vitiligo pathogenesis"
- Dr. Igor Korobko; "Cell biology: faulty melanocyte niche"
- Dr. Brian Lee; "Mechanisms of phototherapy action in vitiligo treatment"
- Dr. Laurent Misery; "Skin neurobiology: impact on vitiligo"
- Prof. Karin Schallreuter; "Oxidative stress in vitiligo"
- Prof. Richard Spritz; "Genetics of vitiligo."

Chairperson: Prof. Robert Schwartz.

Co-Chairs: Prof. Xing-Hua Gao, Prof. Paulo Cunha, Prof. Jana Hercogova, Prof. Henry Lim, Prof. Torello Lotti, Dr. Davinder Parsad.

The discussion will be moderated by the VRF Chief Scientific Director Dr. Igor Korobko, who will provide participants with specific details about this session.

CEO Roundtable Task Force (19.00 – 21.00 on December 14, 2012)

The goal of the CEO Roundtable Task Force is to find the potential correlation between social value and cost-effectiveness of prospective vitiligo treatments, and to answer the key questions surrounding its economics. It is emotionally difficult to put a price tag on suffering, but that is what already happening in many boardrooms across pharmaceutical industry.

The uncertain financial viability for sale of prospective anti-vitiligo treatments offers no incentive for associated investments in R&D. Starting at the individual (micro) level allows work to start on the economic analysis in the absence of complete global prevalence data. The VRF will share its assessment of vitiligo niche markets with the fellow Task Force members.

The emphasis of this meeting is to come to an agreement on the common components necessary to support cost/benefit analyses of the therapy development and individual interventions. The meeting concludes the dedicated Vitiligo day of the World Health Academy congress in the informal setting.

Participants (TBC):

- Mr. Dmitry Aksenov, Founder and President of VR Foundation (USA)
- Dr. Humberto Antunes, CEO Galderma S.A. (Switzerland)
- Mr. Stefan Coccoloni, CEO Safi Medical Care (Italy)
- Mr. Ken Jones, CEO Astellas Pharma Europe (UK)
- Mr. Andy Goren, CEO Dermagenoma (USA)
- Mr. Basudeo Narain Singh, Managing Director Alkem Laboratories (India)
- Dr. Philippe Wolgen, CEO Clinuvel (Australia).
- Chairperson: Yan Valle, CEO VR Foundation.

Co-Chair: Dr. Medhat Abdelmalek, the WHA Congress President.

Expected Outcomes

The results of the Roundtable on Vitiligo will be communicated in plain, practical, and easy to understand language for use by health care providers, researchers, professionals, and officials.

Preceding Events

As a contribution to the development agenda of the Roundtable on Vitiligo, VRF is sponsoring a masterclass and workshop on November 16-8 in Shenyang, China. The workshop will be opened with a keynote speech by Professor Torello Lotti, on how scientists in collaboration with practitioners can standardize, aggregate and analyze data to effectively enhance the quality of the research and quality of life of vitiligo patients.

Accreditation

The Roundtable includes a broad range of representatives from across the healthcare ecosystem, pharmaceutical companies, patient support organizations, World Health Academy, as well as experts and economists.

To inquire about accreditation at the Roundtable on Vitiligo and its Task Forces, please contact Alessandra Fabbri Palmieri at <u>a.palmieri@vrfoundation.org</u> or +39-066-220-7277

The final Roundtable on Vitiligo program will be posted online soon. Please check <u>www.vrfoundation.org</u> for updates.