Innovations in Atopic Dermatitis Care
Pre-Meeting
10th International Symposium on Atopic Dermatitis

Tuesday, April 10, 2018
UMC Utrecht, Van Geuns Building
Utrecht, The Netherlands
Dear Colleagues,

Welcome to the 10th International Symposium on Atopic Dermatitis Pre-Meeting on Innovations in Atopic Dermatitis Care. We are honored to have distinguished guests from all corners of the world who will present lectures on innovations in the field of atopic dermatitis. There will be many areas to be explored in technology and care delivery. We will also have lectures from AD patient organization representatives who will present their experience on patient perspectives and disease management.

We hope you enjoy this exciting session which will bring new perspectives and a fruitful discussion on the care of patients with atopic dermatitis.

Sincerely,

Harmieke Os-Medenderp & Roberto Takaoka
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Atopic Dermatitis in The Netherlands

Bernd ARENTS
The Dutch Association of People with Atopic Dermatitis (VMCE)

About 400,000 people in the Netherlands have atopic dermatitis. The prevalence in children under 12 is about 8%, being the second chronic disease in children, after asthma. The average prevalence is about 2–2.5%. The care of people with AD is mostly organised in so-called first line (90%), the general practitioners. The more severe cases, about 10%, are referred to dermatologists or paediatricians. There are two recognised centres of excellence for AD in The Netherlands: one in Rotterdam for children only, and here in Utrecht for children and adults. Most treatments are insured without co-pay, although the choice of reimbursed emollients is very limited and unsatisfactory. Topical steroids cannot be purchased over-the-counter. Main issue in care for people with AD is lack of information and guidance by physicians, leading to patients being undertreated. Mostly this is due to lack of time and absence of standardised education programmes. Main issue for people living with eczema is that there is not enough awareness of the burden of disease. With its broad network consisting of dermatologist, specialised nurses, pharmacists, researchers, insurers, the government etcetera, the VCME tries to improve the care for people with AD in The Netherlands.

Bernd Arents has had severe atopic dermatitis since birth (1964). In 1996 he started as volunteer for the Dutch Association for People with Atopic Dermatitis (VMCE). He served in many functions, such as secretary of the board (2000–2003) and president of the board (2006–2013). Since 2002 he also dedicates himself to patient advocacy, by participating in national practise guideline development groups, being involved in the national dataset on quality of care for people with AD, participating in research projects, liaising with health care insurers and the government on reimbursement policies, writing for the VMCE member magazine as well as other Dutch dermatology publications, and publishing in medical journals (e.g. systematic review on emollients). For his voluntary contribution to society he received a royal decoration from Queen Beatrix in 2008: Knight of the Order of Orange-Nassau.
eHealth in Atopic Dermatitis

Harmieke van OS-MENDENDORP, RN, PhD
University of Utrecht, The Netherlands

The Department Dermatology and Allergology developed some eHealth solutions. The aim of eHealth is to make good care available, drive self-management, and bring effective and tailored solutions for as many people as possible. All eHealth tools were developed in close cooperation with patients, software engineers and a multidisciplinary team; solutions are tailored to their specific target groups (e.g. parents of children or adult patients) and based on medical guidelines and clinical evidence. The patient website portal is one of the eHealth tools and offers patients real time access to their electronic patient record and the possibility of e-consultations. The online training Living with Eczema supports adult patients and parents of young children with AD in self-management, and consists of information and instructions, videos, patient’s stories, and exercises with feedback and e-consultation. Research studies about the use, effectiveness and implementation of the eHealth tools were carried out and results will be presented.

Harmieke is working as a nurse researcher/epidemiologist on the Department of Dermatology/Allergology of the University Medical Center Utrecht, the Netherlands. She is involved in the development, evaluation and implementation of new interventions to optimize care of patients with chronic diseases like atopic dermatitis, food allergy, urticaria and rheumatoid arthritis. Special focus is on eHealth, such as the patient portal and online self-management trainings (www.umcutrecht.nl/subsite/ehealth), patient reported outcomes, quality of life and health care utilization. Harmieke closely works together with the Dutch patient organization for Atopic Dermatitis and with nurses and dermatologists. Harmieke and her colleagues developed an online course about Atopic Dermatitis for dermatology nurses. She is also lecturer in the Master program of Clinical Health Sciences and supervises master students in Nursing Sciences.
Quality of Life in Moderate to Severe AD Patients in Canada

Amanda CRESSWELL-MELVILLE
Eczema Society of Canada

Quality of life is recognized as a crucial component of health assessment and planning for patient care and improved outcomes. In late 2016 and early 2017, Eczema Society of Canada hosted an online survey to gather insights from Canadians impacted by atopic dermatitis (AD). Data was gathered from over 1000 respondents from across Canada, with both adult and paediatric responses related to satisfaction with health care, wait times, access to therapies, disease management, treatments, sleep loss, absenteeism, and mental health impact. Among adult respondents, 88% suffer with moderate or severe AD. Quality of life impact is significant, with 87% reporting that their day-to-day life is negatively impacted by AD, with 79% experiencing sleep loss, and 32% missing work or important life events due to their AD. Paediatric data was gathered from caregivers and patients aged 13 to 18, with 82% of respondents living with moderate or severe AD. Among the paediatric population, 85% report their AD is not well controlled, and treatment adherence is a challenge for 80% of respondents. Day-to-day life is negatively impacted for 52% of respondents, and sleep is negatively impacted for 70%.

These survey results demonstrate the burden of this chronic, debilitating skin disease. New treatment solutions, improved access to health care providers, and mental health supports are needed for patients and caregivers.

Amanda Cresswell-Melville is the Executive Director of the Eczema Society of Canada (ESC), a national registered charity dedicated to improving the lives of Canadians living with eczema. As leader of the organization, Amanda has fostered significant growth during her tenure, and recently earned a Canadian Dermatology Association Public Education Award.

Amanda has both an Honours Bachelor of Arts degree and a Bachelor of Education. She has also completed the University of Toronto Rotman School of Management MBA Essentials program, as well as the Institute of Corporate Directors Not-For-Profit Governance program. She has worked in corporate training, education, and has served various not-for-profit organizations. Amanda lives in the greater Toronto area with her husband and two children. Her children live with eczema, which inspires and drives her work with ESC.
Education for Patients with AD in the UK

Karina JACKSON
Guy’s and St. Thomas’s NHS, UK

Education for patients with atopic dermatitis (AD) in the UK is provided by range of healthcare professionals. Dermatology nurse specialists play a particularly prominent role. Parental management is key in treating childhood eczema. To be able to manage the condition effectively parents need to have sufficient knowledge, skills and self-efficacy; that is, the belief that they are able to successfully accomplish specific tasks. In 2009 St. John’s Institute of Dermatology developed a novel nurse-led group education programme known as the ‘Eczema Education Programme’ (EEP) with the aim of providing access to structured, evidence-based information to help parents manage their child’s eczema more effectively and confidently. The EEP intervention is delivered to groups of parents by a single dermatology specialist nurse in two, 3-hour sessions. In 2011 we undertook a detailed service evaluation which included; focus group interviews; a questionnaire survey assessing access and satisfaction; pre and post intervention measures of child quality of life measures, disease severity measures, a new parental measure of self-efficacy (PASECI); and service impact data based on General Practice (GP) attendance. The results were favourable and a summary will be presented.

Karina Jackson has over 20 years clinical experience in dermatology nursing in a range of roles and has been a consultant nurse at St. John’s Institute of Dermatology since 2006. As a consultant nurse, her role includes delivering direct patient care to patients with severe inflammatory skin disease and providing clinical leadership and supervision to a team of nurse specialists delivering a range of nurse led services, including topical therapy, wound care and systemic drug monitoring clinics. Her area of clinical expertise is in the management of inflammatory skin disease. She has worked in specialist adult psoriasis and eczema services for many years. She works within a multi-disciplinary team and leads a dermatology day treatment centre for adult patient admissions. She is a strong advocate for developing holistic services for people with skin disease and has successfully led the recruitment of clinical psychologists to support local dermatology services. She has developed a dermatology care course for nurses in collaboration with KCL University and regularly teaches and lectures in a number of fora. She is the consultant editor for ‘Dermatological Nursing’ journal. She has a special interest in patient education programmes and has developed a nurse led group ‘Eczema Education Programme’ for parents to support self-management.
The positive effect of shared decision making (SDM) on health outcomes is well documented. Studies show shared decision making promotes patient autonomy, builds trust with providers, improves patient safety and increases health outcomes. Moreover, SDM contributes to enhanced patient satisfaction and reduced medical costs.

To that end, the National Eczema Association (NEA) is building a SDM/Eczema Health Platform that is a desktop and mobile-based application for people with atopic dermatitis and other forms of eczema to track everyday “inputs” such as food, allergens, sleep and stress, alongside disease-specific symptoms such as flares, itch and pain. Additionally, the platform helps them work with their provider via appointment preparation tools, decision aids, appointment trackers and access to care resources.

The health platform has two objectives:
- Activate patients with moderate to severe atopic dermatitis, and
- Collect real-world data to address gaps in understanding of burden of disease.

These objectives support the overarching goal of the platform, which is to improve health outcomes of atopic dermatitis patients.

Julie Block, President and Chief Executive Officer of the National Eczema Association since 2010, has dedicated her career to the non-profit sector, and for the past several years, to patient-health advocacy.

Julie’s extensive non-profit management, strategy and development experience stems from leadership positions in education, medical technology, and the arts. At Harvard Medical School, she directed a variety of programs and new initiatives, including the launch of a new AIDS research center in the 1980’s. Throughout her career, Julie has continued her involvement with causes she is passionate about as a volunteer including the American Cancer Society Relay for Life, the Susan G. Komen Breast Cancer Foundation, and Very Special Arts for children with special needs. Julie holds a Bachelor in Arts in Liberal Arts, and received her education at University of California at Santa Barbara, San Diego State University and Harvard University extension.

Julie BLOCK
National Eczema Association, USA

Shared Decision-Making in Atopic Dermatitis
Design Thinking in Atopic Dermatitis

Roberto TAKAOKA, MD
University of São Paulo, Brazil

Design thinking is a creative innovation process originally used by designers to enhance the look and functionality of products. More recently, this methodology has been used to tackle complex social and health care problems. Design thinking is a human-centered approach that, when applied to health care, involves creating solutions by listening closely to patients' needs and problems. Design thinking shows us that, in order to be effective, the management of AD must constitute a much broader approach, encompassing emotional, social, cultural and financial factors. Prevention and health promotion should be encouraged. A collaborative work among patients, families, doctors and a multidisciplinary health care team should be established to create a better treatment for atopic dermatitis.

Roberto Takaoka is a dermatologist from São Paulo, who has worked in the field of atopic dermatitis for more than 25 years. After finishing his Dermatology Residency at the University of São Paulo Medical School, he worked as Research Fellow at the Oregon Health & Sciences University, mentored by Prof. Jon Hanifin. After returning to Brazil in 1990, he opened the Atopic Clinic at the University of São Paulo Medical School Hospital, which he continues to run to this day. Roberto founded the Brazilian Atopic Dermatitis (AADA) in 1997 after many years of experience with support groups for patients with atopic dermatitis at the University of São Paulo Medical School. AADA’s current mission is to transform the disease into an opportunity for growth and self-development. Projects include the creation of support groups for patients and their families in other Brazilian cities, creation and distribution of educational materials, art workshops, and organization of scientific meetings for doctors and other health care professionals. Roberto is also interested in art and design and has attended courses on Innovation and Social Entrepreneurship at the Massachusetts Institute of Technology (MIT) and the Stanford Graduate School of Business.
Wet Wrap Dressing & New Skin Barrier Measurement Device

Hyunjung KIM, MD
Seoul Medical Center, South Korea

Wet-wrap treatment (WWT) is a crisis intervention modality in severe atopic dermatitis. The purpose of our first study was to produce the tutorial video about Outpatient Home-based Wet Wrap Dressings with Topical Steroids with patients with severe recalcitrant atopic dermatitis. To get the patients’ (or patient’s caregivers’) centered video, we used the tool of service design and co-design methods. We stepped up as 4 parts, Discover, Define, Develop and Deliver. This video is the first use case of design thinking for atopic dermatitis patients in Korea and is the most useful educational video at present.

Our object of second study is that regular measurement of TEWL can be of help for improving the skin Barrier function, and of therapeutic benefit for skin diseases, such as Atopic Dermatitis.

We did the Clinical study of AD patients to explore the therapeutic effectiveness of daily IoT base skin barrier function measurement for atopic dermatitis therapy. This study demonstrates that this new device can easily measure the skin barrier function on a daily basis with the same performance as the existing equipment at low cost.

Dr. Hyunjung Kim is the Director of the Department of Dermatology/Atopy Clinic and the Principal Researcher at the Department of Environmental Health Research, Seoul Medical Center (SMC). Since 2015, she also has been the head of the Human Understanding Design Centre (HUDC) at SMC. She has been trained as a researcher for skin barrier in Dr. Peter Elias lab at the University of California San Francisco. Her research interests are Atopic Dermatitis and Skin barrier. She is also an expert in the education programme for atopic dermatitis patients. She fulfils as the chairperson of practical affairs in Seoul Atopy Asthma Information Center and as Atopy and Asthma special consultant for Seoul Metro City Health Promotion Working Group. She is devising ways to improve patient-friendliness and experience through various design thinking process in the education of patients with atopic dermatitis.
Atopic dermatitis (AD) is a chronic relapsing skin disease prevalent in 1% to 3% of adults in Western industrialized countries. We sought to investigate the effectiveness of educational training in an outpatient setting on coping with the disease, quality of life, symptoms, and severity in adults with AD. In this German prospective, randomized controlled multicenter study, adult patients with moderate-to-severe AD were educated by referring to a comprehensive 12-hour training manual consented by a multiprofessional study group from different centers (Arbeitsgemeinschaft Neurodermitisschulung für Erwachsene [ARNE]). This is the first randomized, controlled multicenter study on patient education in adult AD. The ARNE training program shows significant beneficial effects on a variety of psychosocial parameters, as well as AD severity.

Prof. Uwe Gieler is a dermatologist, allergologist and a physician of psychosomatic medicine and psychotherapy. He is also the Vice-chair of the Department of Dermatology and Allergology at the Giessen Medical University, Germany and part-time member of the Department of the Psychosomatic Medicine of the same medical university. Head of the Atopic Dermatitis School, Academy Hessen and Vice Chair of the German Society of Atopic Dermatitis Education. Head of Psychotherapy Education Academy of Hessen for Physicians and Psychologists. President of the European Society of Dermatology and Psychiatry (ESDaP). Uwe has a special interest in atopic dermatitis education, compliance, psychodermatology and psychoimmunology and has published many books and more than 150 papers and several international journals.
Digital Tools for Scoring Atopic Dermatitis – Opportunities and Challenges

Prof. Jean-François STALDER, MD
University of Nantes, France

Prof. Stalder trained in Pediatrics and Dermatology and in 1997 became the Head of the Department of Dermatology in the Nantes University Hospital in 1997. President of the Scientific Committee of the “Fondation Dermatite Atopique” Chairman of the French Groupe d’Education Thérapeutique (GET).

Main research area includes atopic dermatitis, therapeutic education programs (TPE) in dermatology, pediatric dermatology Prof. Stalder was involved in the creation with Pr Alain Taieb of the European Task Force on Atopic Dermatitis (ETFAD) 1990 and the SCORAD index (1996). Also created the the first Atopic School in France in 2000 and the international patient oriented network in dermatology (OPENED) in 2007 Co–designer of a self assessment score (POSCORAD), and topical corticophobia score (TOPICOP).

Fig. PO–SCORAD

Prof. Stalder wrote more than 200 articles in journals and chapters in books in the fields of atopic dermatitis and pediatric dermatology. Participated as board member and investigator in many clinical trials and helped design several multimedia programs in the field of atopic dermatitis, pediatric dermatology (applications, web sites, CDRom).

“I am convinced that multiple international transdisciplinary approaches are the only way to go forward with the aim to better manage patients suffering from Atopic Dermatitis, and that a patient–oriented approach is essential to help all of us to improve our practice.”
Atopic Dermatitis Organizations

The Dutch Association for People with Atopic Dermatitis (Vereniging voor Mensen met Constitutioneel Eczeem, VMCE)

The Dutch Association for People with Atopic Dermatitis (Vereniging voor Mensen met Constitutioneel Eczeem, VMCE) was founded in 1994 by four people with severe atopic dermatitis (AD). Helped by prof. Brujinzeel-Koomen, who is the host of ISAD 2018, the VMCE has evolved into a national acknowledged organisation who speaks on behalf of people with atopic dermatitis.

The objective of the VMCE is to improve the well-being of people with AD. Main activities are: bringing people with AD together in face-to-face meetings and online, giving adequate and correct information (brochures, magazine, website, books and dvd) and advocating on behalf of people with AD in the broadest sense of the word. The VCME is a voluntary based organisation (approx. 60), while administrative tasks are carried out by an office that is shared with 20 other patient organisations. It is funded by membership fees, advertising (non-pharma) and a government subsidy.

Eczema Society of Canada

Eczema Society of Canada (ESC) is a registered Canadian charity dedicated to improving the lives of Canadians living with eczema. ESC’s mandate is that of education, support, awareness, advocacy, and research. ESC offers patient and health care provider education, has support volunteers across the country, and funds research efforts through a competitive research grant program. ESC also advocates for Canadian eczema sufferers to ensure access to the best treatment and care.

https://eczemahelp.ca
National Eczema Association (NEA), USA

The National Eczema Association (NEA) is a non-profit 501(c) (3) organization whose mission is to improve the health and quality of life for individuals with eczema through research, support, and education. In the United States alone, over 10% of the population has some form of atopic dermatitis/eczema. NEA was founded in 1988 by a group of patients, medical professionals, and parents who decided they could do something more to make living with this skin disease a great deal easier.

Through a variety of educational materials, including a patient-oriented magazine, a monthly electronic newsletter, and social media channels, NEA reaches a diverse audience that includes eczema patients, caregivers, medical professionals, industry, policy makers, and other stakeholders. NEA also conducts day-long forums, patient conferences and participates in a wide-variety of medical symposiums.

As the sole patient advocacy organization serving people with eczema, NEA is active year-round to promote eczema awareness and address issues critical to patient care. Advocacy efforts include advancing increases in skin disease research funding through the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) of the National Institutes of Health, as well as increasing public understanding regarding the burden of eczema.

Brazilian Atopic Dermatitis Association (Associação de Apoio à Dermatite Atópica)

AADA was founded in 1997 following many years of experience with support groups for patients with atopic dermatitis (AD). The association is composed of patients and their families, doctors, psychologists, nurses, social workers and volunteers. AADA’s current mission is to transform the disease into an opportunity for growth and self-development. AADA’s activities include: creation of educational material about AD; organization of support groups for patients and their families; art workshops: painting, origami, music; educational workshops: relaxation, skin hydration; and scientific meetings for doctors and other health care professionals.

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aada@aada.org.br