

The International League of Dermatological Societies - Newsletter

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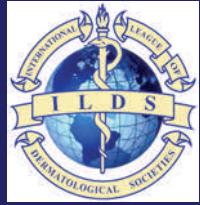
Progress in improving the lives of patients with albinism in sub-Saharan Africa

By Rod Hay, Colette van Hees, Claire Fuller, Rosemarie Moser.

Albinism is a common genetic disorder in sub-Saharan Africa. Although precise figures are still hard to validate it is estimated in Tanzania, for instance, that there over 1,1800 new born infants are affected. Unprotected from the tropical sun, those with albinism experience a high incidence of aggressive non-melanoma skin cancer, severe visual impairment as well as social discrimination and persecution. There has been an increasing focus on the issues facing these patients largely because of work undertaken by voluntary groups but dermatologists in particular have been prominent. Publicity over the murder of individuals with albinism in Africa has drawn public and legislative attention in order to seek solutions.

Fifteen years ago the Regional Dermatology Centre (RDT) in Moshi Tanzania started an outreach programme amongst patients with albinism (PWAs) to provide sunprotective clothing and to detect skin cancers at an early stage and age. The Director and local clinical officers with dermatologists from different parts of the world such as Barbara Leppard, Don Lookingbill and Jim Nordlund established a service which is turning the tide by vastly reducing the incidence of inoperable and advanced skin cancers by intervening early and dealing with actinic keratoses and early small skin cancers. Over the past year there has been an expansion in this work led by the local team, John Masenga, Henning Grossman and Alfred Naburi. Similar work is being carried out in other parts of sub-Saharan Africa such as Malawi (Colette van Hees, Levson Mwale, Rosemarie Moser, Frederick Mtoto) which has widened the vision for caring for patients with albinism (PWAs). Taking a broader approach to the media, the Hats on for Skin Health project, a joint initiative between Stiefel and the ILDS/IFD, drew further attention to the plight of the African albino highlighting both the risks of cancer and blindness as well as severe discrimination and stigmatisation. In recognition of the importance of expanding this project, a new building named the "Care Unit for Persons with Albinism (CUPWA)" has been erected in the grounds of the RDT (Photo 1) and it will house two new initiatives. The first is a pharmacy and compounding facility which, under the leadership of Mafalda Soto, a Spanish pharmacist, has developed a cost effective sun screen, Kilimanjaro Sun Care, for total sun protection. The building is also used as a training resource for local and outreach training in sun protection (Photo 2). In the second part of the building a training workshop is being established which is run by PWAs and which will be used to teach patients the essentials of machine sewing to help them to earn a living by working inside sheltered from the sun (Photo 3). The increasing focus on assisting patients with albinism living in sub-Saharan Africa has recently resulted in three important new events in Tanzania which will improve their care.

Firstly the Regional Dermatology Unit Albinism Team extended their outreach control work by visiting an additional area; Singida, a district beyond Arusha where they saw more than 250 PWAs whom they treated with cryotherapy and instructed in sun protection and the use of sunscreens. They distributed hats to all those attending. The work formed part of a very successful Tanzanian National Albino Day that took place in Singida Region with the Minister for local Government, accompanied by the Deputy Minister of Health, as the Guests of Honour. Mafalda Soto demonstrated the use of the sunscreens and discussed their preparation. This work is supported by the ILDS and IFD through Hats on for Skin Health and also the Tanzanian Albino Society, Under the Same Sun (an international NGO based in Canada) and the International Rotary. The joint work has paved the way for increasing co-operation to ensure better treatment for PWAs.



The RDTC team also met the Prime Minister of Tanzania who attended a Seminar on Albinism Dodoma, Western Tanzania. He was accompanied by the Speaker and many Members of Parliament. Professor John Masenga, principal of RDTC was able to brief these ministers on the medical management of albinism and the programmes for care of PWAs based in the RDTC. The Prime Minister was very supportive of the work being carried out in Moshi and complemented the team on their work and on the local production of sunscreens.

The seminar also prompted the United Nations Human Rights group into drawing attention to the problems confronting PWAs in Africa when in their regular contribution to the UN Daily News (<http://www.un.org/apps/news/story.asp?NewsID=448250>) they noted the regular mistreatment and persecution of albinos and that non-governmental organizations working in the field had documented 186 ritual attacks against people with albinism since 2000. Abductions and killings have been recorded in 15 African states. Resolutions from UN Human Rights representatives included the need for health authorities to assess the health needs to ensure that albinos are accorded equal access to good health care and for schools to adopt measures that can provide appropriate education for children with albinism. As one human rights expert said "They are not ghosts; they are simply people such as you and I but living with albinism "

In Blantyre, Malawi in March 2013 there was an albinism awareness day organized by the local dermatologist clinical officers trained at the RDTC, helped by European dermatologists Collete van Hees (Netherlands) and Rosemarie Moser (Austrian). A number of other organizations participated including the albinism association of Malawi and Federation of Disability Organizations of Malawi. Patients received donated hats and sunscreens and the day was widely publicized by the local and national press. After the public session patients with albinism were screened and treated for both cancerous and precancerous lesions (Photo 4). Aisha Sethi (Chicago) has also been very active in publicizing the problems faced by PWAs in the region. Other centres of similar activity include Mali, Uganda and Kenya.

These stories are merely examples of a growing collaboration between dermatologists, NGOs, voluntary organizations and governments to improve the situation. While progress is slow these contributions have contributed to a steadily rising interest in affording proper medical care to albino patients and in ensuring that they can live safe lives in their own communities without fear of discrimination or violence



The new Care Unit for Persons with Albinism at the RDTC in Moshi Tanzania



Dr Moser treating a patient in Malawi



One of the PWA instructors showing her goods, RDTC



Talking about sun protection, Tanzania

WCD 2015 - Vancouver

WCD 2015 Sneak Preview Symposium in Hong Kong – July 2013

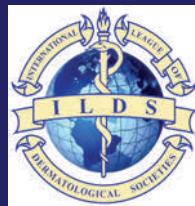
Join us in July at the Asian Dermatological Congress in Hong Kong, for another 23RD WCD Preview Symposium. We initiated this Preview Session at the Miami AAD meeting in March, 2013 with our Countdown and Preview Symposium, where we featured renowned international speakers. The session was aimed at giving attendees a taste of the quality and diversity of the program they can expect at the 23RD WCD in 2015. Registration and Housing for the 23RD WCD in Vancouver will be opening soon. Make sure

to “like” us on Facebook at Derm2015 and follow us on Twitter @Derm2015 to track our progress and join the conversation. Take part in our *I'll Be There* promotion and have your picture included on the website. To learn more contact the Congress Secretariat at info@derm2015.org.

Please send us your name, mailing and email addresses, so that we can update you on our progress and news. For more information, visit our website at: www.derm2015.org.

**Jerry Shapiro, MD, President
Harvey Lui, MD, Secretary-General**

23RD WORLD CONGRESS
OF DERMATOLOGY
VANCOUVER 2015



Congress Center Vancouver

ILDS Certificate of Appreciation

Award recipient

Vincent A. Cipollaro
Luitgard G. Wiest
Jürgen Knop
Jouni Uitto



Vincent A. Cipollaro having been presented with the 2012 ILDS Certificate of Appreciation in Miami in March 2013 at the International Society of Dermatology Reception



Jürgen Knop being presented with the 2012 ILDS Certificate of Appreciation at the German Dermatological Society's Annual Meeting in Dresden in May, 2013

Luitgard G. Wiest being presented with the 2012 ILDS Certificate of Appreciation in Miami in March, 2013 at the American Academy of Dermatology Recognition Lunch



Antti Lauferma, Jouni Uitto,
Veli-Matti Kähäri, Sirkku Peltonen

Jouni Uitto having been presented with the 2012 ILDS Certificate of Appreciation by Antti Lauferma (President of the Finnish Dermatological Society) at the International Society of Dermatology Reception in March 2013



Members' Corner

International Psoriasis Council

IPC Symposium: "Stratifying Psoriasis: Methods & Clinical Utility"

On May 7, 2013, IPC sponsored a satellite symposium at the International Investigative Dermatology (IID) Congress in Edinburgh, United Kingdom. The objective was to identify mechanisms by which psoriasis populations can be subdivided, with a view to delineating susceptibility to disease and better responses to treatment. More than 130 participants attended the symposium, which was led by Catherine Smith (St John's Institute of Dermatology, London) and Errol Prens (Erasmus University, Rotterdam), who also made presentations on "Why Stratify Psoriasis?" and "Immunological Biomarkers of Treatment Response," respectively. Also making podium presentations were J.T. Elder (University of Michigan, Michigan), "Genetic approaches to stratification;" Gertjan Wolbink (Sanquin Blood Supply, Amsterdam), "TNFi Immuno-genicity;" James Krueger (Rockefeller University, New York), "Advances in Tissue Transcriptomics;" and Mike Barnes (Queen Mary's University, London), who highlighted methods of integrating data to support stratification. A summary publication of the symposium is currently in development.



IPC's Genetics Project: "Towards Completing the Genetic Map of Psoriasis"

IPC continues its aggressive clinical study, which is designed to genetically type rare, protein-altering variants in more than 10,000 psoriasis cases and 10,000 controls. The information might help clarify the genetic architecture of psoriasis, resulting in better targeted therapies and the development of markers to monitor disease progression and drug responsiveness. IPC continues to raise sponsorship funds for the project, which currently is being performed by investigators from the genetic research laboratories of Professors J.T. Elder and Goncalo Abecasis (University of Michigan, U.S.); Jonathan Barker and Richard Trembath (King's College, London, UK) and Andre Franke (Christian-Albrechts University, Kiel, Germany). The international collaboration is expected to lay the groundwork for innovative approaches to treatment strategies, as well as to define the therapeutic response to treatments in specific psoriasis patients by building a bridge between the genotype and phenotype of the disease. A summary manuscript related to the project has been published: "The quest for psoriasis susceptibility genes in the post-genomewide association studies era: charting the road ahead," Capon & Barker 2012, Br J Dermatol, Jun;166(6):1173-1175.



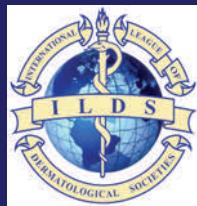
Taiwanese Dermatological Association (TDA)

Reported by Thomas Chu, MD

The 2013 Spring Meeting of the Taiwanese Dermatological Association (TDA) and the first inaugural Taiwanese Dermatology Aesthetic Conference (TDAC) were successfully held on May 4th and 5th in the vibrant city of Kaohsiung, located in southern Taiwan. More than 1000 attendees gathered at the International Convention Center Kaohsiung (ICCK), located in this beautiful southern city, which started as a small trading village

that grew into a major global shipping port to become the second largest city in the country. The event featured distinguished international speakers from Australia, Canada, China, Hong Kong, Japan, Singapore, South Korea, United Kingdom, and United States. In keeping with the core mission of "skin health and beauty", the meeting sought to advance the quality of dermatologic

care and to improve skills and competence in areas of aesthetic dermatology, dermatological surgery, pediatric dermatology and medical dermatology. We were very honored to have Professor Jerry Shapiro, President of the upcoming 23rd World Congress of Dermatology in Vancouver (2015), speak and moderate at our hair forum.



Dr. Shapiro, who is the foremost hair expert and director of Hair Transplant Center Vancouver at University of British Columbia, presented the latest updates on finasteride for male pattern hair loss. Other esteemed guests for the hair forum included Dr. John P. Cole of Cole Hair Transplant Group, as well as Dr. Wenyu Wu, Vice Chairman of China Dermatologist Association.

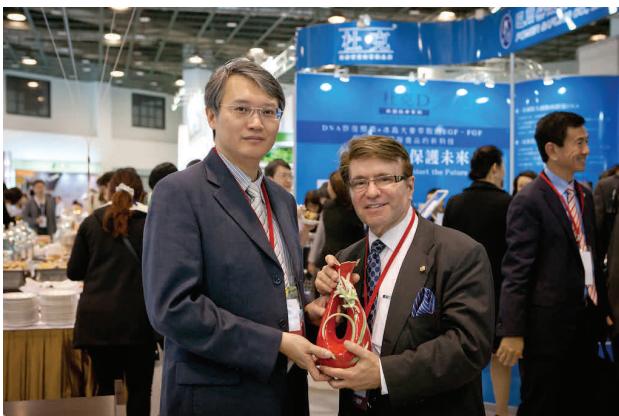
We were also very privileged to have Professor Ronald Moy of UCLA, the 2011 President of the American Academy of Dermatology, lecture on what is new and next in dermatological surgery and procedures. Dr. Moy also Presented on new anti-aging skin care with topical therapy containing epidermal or fibroblast growth factors. Highlights of the conference included real-time, live cadaver demonstration from the Clinical Anatomy Skills Center from the Royal College of Physicians and Surgeons of Glasgow at the University of Glasgow. Professor Steven Feldman from Wake Forest University School of Medicine emphasized the importance of

simplifying topical therapy regimen and using biologics when indicated to improve adherence, treatment response and satisfaction of psoriasis patients. Professor Chee Leok Goh of National University of Singapore and Dr. Henry Chan, the 2012 President of the Hong Kong College of Dermatologists, lectured on the latest trends in lasers technology. For the advanced injection workshops, our honored international guests included Dr. Nark-Kyoung Rho of Sunkyunkwan University of South Korea, Dr. Hema Sundaram, associate editor for the Journal of Drug in Dermatology, and Dr. Greg Goodman, associate professor of Monash University Melbourne, Australia. Dr. Brian Zelickson, 2011 President of the American Society of Laser Medicine and Surgery, focused on the newest procedures in non-invasive fat reduction. With her extensive research endeavors, Professor Adelaide Hebert of University of Texas – Houston Medical School presented findings on pediatric

dermatology and atopic dermatitis. Professor Genji Imokawa of Tokyo University of Technology shared his interest and findings on the role of ceramide in atopic dermatitis.

Although the sessions were all held in English, simultaneous Mandarin interpretations were available during the meeting.

Under the leadership of our newly elected and the youngest TDA President, Dr. Chih-Hsun Yang, the key organizers such as Drs. Po-Han Huang, Ming-Tsan Wang, Nai-Ren Hsu and Ren-Yeu Tsai, with the help of others, worked tirelessly with dedication to make this a well-organized and well-attended meeting.



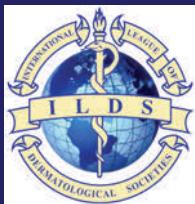
Future Events

For announcement of future events, please follow these instructions:

Visit our website: www.ilds.org

Click on "Events" and "Add a New Event" and insert all the details

After you inserted all details, please advise Eve Arnold on admin@ilds.org who will then place the insertion onto the site.



German Dermatological Society (DDG)

Reported Jan Simon

Biannual meeting of the German Dermatological Society (DDG)

The traditional 47th biannual meeting of the German-speaking Dermatology was held in Dresden, Germany May 1st to May 4th 2013. Over 3200 Dermatologists from Germany, Switzerland, Austria as well as many international guests attended this conference. In 37 symposia, 11 plenary talks, 18 courses and many lunch time and afternoon seminars recent developments in both research and patient care in dermatology were presented. The extraordinary diversity of dermatology was reflected in the programme covering dermatooncology, allergology, dermatosurgery, dermatopathology, infectious diseases, inflammatory skin diseases, molecular diagnostics among many others.

A novelty of the 47th DDG conference was the symposium "International Dermatology" in which renown speakers from France, the Czech Republic, Poland, Lettland, the Slovakian Republic, South Korea and Greece gave key note lectures. Moreover, a joint symposium of the DDG and the German National Academy of Sciences Leopoldina was held.

"The DDG conference provides an excellent overview of the recent advances in dermatology, which can be transferred directly into our daily work for the benefit of our patients" says congress President Prof. Dr. Rudolf Stadler, Minden, Germany. In addition to the scientific programme, several honours and awards were presented, both to highly esteemed leaders in dermatology honouring their life time achievements as well as to young dermatologists honouring their success in dermatological research and patient care.

For the third time the German Dermatological Society sponsored an art exhibition by the students of the Dresden International College of Arts focussing on the theme skin and arts.

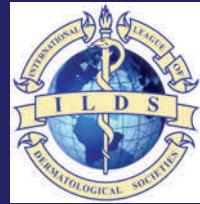
The DDG conference is held every 2 years alternating with the conference "DDG compact", a new format of containing medical education in dermatology which focuses on selected topics within dermatology.

DDG conference Dresden,
over 3200 participants



Dermatology meets the arts,
congress President Prof. Dr.
Rudolf Stadler opens the vernissage
at the Dresden College of Arts





2nd World Congress of Cutaneous Lymphomas & 6th International Symposium on the Biology and Immunology of Cutaneous Lymphoma

Reported by Marten Vermeer, Peter Walden

The 2nd World Congress of Cutaneous Lymphomas (WCCL) and the 6th International Symposium on the Biology and Immunology of Cutaneous Lymphoma (ISBICL)

were jointly held from 6 to 9 February 2013 in Berlin, Germany under the auspice of the International Society of Cutaneous Lymphoma (ISCL), the United States Cutaneous Lymphoma Consortium (USCLC) and the European Organization for Research and Treatment of Cancer Cutaneous Lymphoma Task Force (EORTC-CLTF), and organized by the Department of Dermatology, Venerology and Allergology of the Charité – Universitätsmedizin Berlin. With the conference, the translational research focus of the ISBICL series was combined with the clinical research focus of the WCCL. With more than 350 delegates including clinical and basic researchers from all cutaneous lymphoma centers worldwide, and above 200 scientific contributions it was the largest meeting on the topic so far.

The aim of the conference was to review the current state and the prospects of the research on the molecular and cellular causes of cutaneous lymphomas and related cancers, and the latest in the development of new therapies and diagnosis. A number of reports emphasized the opportunities arising from the new insights provided by genomics and expression studies on cutaneous lymphomas. Specifically, whole exome sequencing and new array platforms have discovered exten-

sive alterations in promoter methylation and microRNA expression as well as multiple mutations in cutaneous lymphoma tumor cells. Discussions pointed at the need to bridge the gap between these new technologies and the morphology-guided clinical and histopathological diagnosis. The newly introduced concept of topomics attempts this with an integrating multiparameter immunostaining approach to map the molecular topology and co-localization of numerous factors in tissues. This led to discussions on whether and how far new computer and information technologies can help to exploit the information from the new technologies for personalized medicine. Would, for instance, a virtual patient be possible and instrumental to test potential effects of alternative treatments *in silico* prior to clinical application? In addition to these genome wide approaches several studies investigated the diagnostic value of specific genetic lesions and/or expression of proteins by tumor cells. New targeted therapies, antibodies specific for cell surface molecules that direct toxins or immune effector mechanisms against the tumor cells or inhibitors of kinases that drive tumor growth, have entered clinical development; some are already at advance stages, and a large number of presentations reported their outcome. Given the potentials of these therapies, the discovery of new targets and the development of new probes to address these targets was of

high interest and topic of a number of sessions on new prospects for therapy development. One session was devoted to difficult to treat and rare lymphomas. The state of the art of current therapeutic approach was presented and the development of new therapeutic strategies was discussed, specifically the place for stem cell transplantation for aggressive lymphomas. Given the need for new therapeutic targets in cutaneous lymphomas the molecular cell biology sessions (focusing on cell signaling and apoptosis induction) and immunology sessions were of great interest as these gave insight in the molecular pathology of this disease but also provided novel strategies to treat cutaneous lymphomas.

The contribution of clinicians as well as basic scientists to the different themes of the conference ushered in ample opportunities for discussions across disciplines which was felt to be productive for both sides. The conference series will be continued along these lines to be a forum for clinical and translational research of the cutaneous lymphoma and related communities.