



4th Annual International Albinism Awareness Day Celebrations - Jinja, Uganda, 13 June 2018



The guest of honour launching the cryogun

This year's International Albinism Awareness Day was celebrated under the theme, "shining our light to the world".

The theme offered the opportunity to celebrate the achievements of persons with albinism. Over the past year, there have indeed been many achievements in the fight for our rights.

First, the Government of Uganda agreed to our most urgent advocacy request, and waived import duty and taxes on sunscreen lotions. This decision is already having an impact on the lives of persons with albinism: through this and other measures by SNUPA and partners, we estimate that in Busoga sub-region, the death rate for persons with albinism below the age of 40 has already decreased from 98% to 70%. We hope to see more improvement in the entire country.

Second, our advocacy with the most senior government officials has gone from strength to strength. The support of the Right Honourable Speaker of the Parliament Rebecca Alitwala Kadaga has been invaluable. The Speaker wrote to the President of Uganda His Excellency Yoweri Museveni to share some of our top priorities on healthcare, education and employment. We also had the opportunity to communicate some of our requests to the President in person, when the SNUPA band was invited to perform for him at the International Disability Day commemorations last December.



The SNUPA band meeting the president during the 2017 International Disability Day commemorations

Third, our engagement at the international level continues to grow and grow. Earlier this year, SNUPA's Chairperson Peter Ogik represented persons with albinism in Uganda at a consultation on the Regional Action Plan on Albinism. Mr Ogik also represented persons with albinism and the entire disability movement at the Commonwealth meetings in London in April.

The theme, "shining our light to the world" is also perfect for raising awareness about the capabilities of persons with albinism, and shattering myths about the condition. SNUPA designed the day's celebrations so as to have maximum awareness raising impact.

As an innovation for this year, we stepped up our pre-event activities. This included a very busy schedule of media work involving many national and local TV, radio and print outlets (who, unusually allowed us to disseminate our messages for free because they support our work). We estimate that the combined audiences of these media is over 20 million people. In this way, International Albinism Awareness Day gave us an opportunity to reach even those who could not physically attend the event in Jinja. We also used the opportunity to raise awareness locally, driving around Jinja town on the eve of the event with dancers with albinism from the SNUPA band who drew a crowd to hear our messages.

Attendance at this year's event was even a little higher than the record that we set last year. 753 persons with albinism attended, including people who travelled from far beyond Uganda. Thousands of persons without albinism also attended – a key part of our awareness raising strategy. The event drew a very wide mix of people from across the community, ranging from the local bikers club to Deaf children from a local school (we believe strongly in unity within diversity and always aim to make the event inclusive of other impairment groups).



Persons with albinism smartly dressed in SNUPA attires

We used many different strategies to shatter myths about our condition on the day. The SNUPA band is now very well known for its 'edutainment' performances, which combine very well-liked music and dance with informative messages on the rights of persons with albinism. This year we have produced a CD, which we are using to raise awareness and generate income for our activities.

In addition, we arranged for the Uganda blood bank to attend the event, and many persons with albinism donated their blood. As well as helping to mitigate the blood shortage in the country, this was also an important symbolic act for shattering myths. According to some false beliefs, persons with albinism do not have red blood like other people. This mass blood donation gave us an opportunity to shatter this myth and to show how much persons with albinism want to make a contribution to our communities alongside our brothers and sisters without albinism.



Persons with albinism taking lead in donating blood

The highlight of the day was the speeches. We were privileged that our guests included members of Parliament; the Jinja District LC V Chairperson; the Minister for Youth and Information Communication Technologies from the Busoga Kingdom; representatives from the National Council For Disability and the National Union of Disabled Persons of Uganda; the Commissioner Elderly and Disability; the Uganda Media Caucus on Disability; the Chief Administrative Officer of Jinja District; Jinja Central District; ADD International; many journalists and other local stakeholders. We greatly appreciated inspiring speeches from a number of the important guests who were present.

We were deeply honoured to welcome the Right Honourable Speaker of the Parliament Rebecca Alitwala Kadaga as our Chief Guest. What is more, the Speaker's speech contained exciting new commitments to action, including that:

- The Commissioner Elderly draw up a National Action Plan on albinism by the end of the year. Jinja District Local Government will draw up a local action plan.
- The Commissioner Elderly and Disability and Disability together with the ministry of education will develop a cabinet paper covering procurement of sunscreen lotions, sunglasses, hats as UPE (Universal Primary Education) and USE(Universal Secondary Education) materials and distributing such items to schools that have learners with albinism.
- Member of parliament for persons with disability to ensure Key priorities of persons with albinism (as per the Speaker's letter to the President) are presented in the respective committees for consideration in parliament.
- The Commissioner Disability and Elderly should conduct research on the incidence of albinism in different parts of the country, and should propose policy responses.
- The SNUPA band should be invited to the Commonwealth Parliamentary Conference in 2019 (as recommended by the Hon. Hellen Grace Asamo in her speech).

The Speaker welcomed proposal that the UN Independent Expert on Albinism, Ms Ikponwosa Ero, should make an official visit to Uganda.

The speaker also thanked SNUPA for her advocacy work on albinism, “I want to thank Mr. Ogik and your team for the campaign. It takes a lot of courage to advocate for those issues. I am glad to say that I admire your courage, I commend you, continue doing the advocacy. You have changed the attitude of people in Uganda”, said the speaker.

The events concluded with the launch of several new SNUPA initiatives and activities, including a cryogun for skin precancerous treatment, and a new web page dedicated to news on albinism issues through which we hope to spread our messages even wider.



The speaker launching the news website for albinism news www.pats-journal.com

SNUPA with her expertise pledges to work closely with the commissioner and the line ministries on issues about albinism as outlined above.

In conclusion, this year’s event surpassed our expectations. With so many exciting opportunities opening up, SNUPA looks forward to “shining our light to the world” even more brightly in the year to come. Special thanks to our partners Jinja district local government, the Lush Charity Pot, Advantage Africa and other stakeholders for making the function possible.

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