MAY 2023 HOSPICE **AFRICA IRELAND** *Newsletter*

HELLO FROM HAI!

Summer is nearly here and we are pleased to share with <u>you our first newsletter for</u> the year.

Contents:

- Rory's visit Meet the board
- Updates from Uganda
- An AGM to remember
- **Reflections from Hoima**



First we hear from Rory, who visited HAU last year. He shares his experience below.



In my brief visit to Uganda, there are several enduring memories. The hospitality, the warmth of welcome and the kindness shown by all. This kindness was exemplified during my trip to Little Hospice Hoima. We visited an elderly man with motor neuron disease, who lived in a two-room house about half an hour outside of Hoima. He sat unable to speak in the corner of the living room, cared for by his wife. After our visit, she insisted on gifting us mangoes. Before we could protest, this elderly lady disappeared and returned with a fifteen-foot-long stick. She then sent a young child up into the mango tree by the road – she knocked mangoes out of the tree with the stick, while the young boy threw them down from above. It was only when back in Andrew Kaggwa House that Doctor Anne so succinctly summed up the story - "Those who have little give it all, while those who have plenty give nothing".

The care and compassion are what strikes you first. Listening to the team of clinical nurses discuss the patients, their patients. Tirelessly working over the weekend to ensure that patients receive necessary pain relief or emotional and spiritual support. The patients too, however, are patients of HAU. The families are forever grateful for the support and care that hospice provides their loved ones. This is reflected in their willingness to return and work with hospice - mostly as community volunteers. All wanted to give back to Hospice, to help, because they had been helped.



A massive thank you to all in HAU and Andrew Kaggwa House for allowing this curious mzungu to see, first hand, the impact of the amazing work being done on a daily basis. Text and photos by Rory O'Sullivan-Sexton

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Want to donate? Please visit our online donation page: https://donorbox.org/hospice-africa-ireland or you can text 'HAI' to 50300 to make a €2 donation.



Michael Corless Chair of the Anne Merriman Foundation



Michael was introduced to Dr Anne in October 2018 whilst visiting Liverpool. He first visited HAU in January 2019 as an observer, and spent 12 weeks in different Uganda at intervals throughout the year. He was appointed to the Board of HAU in September 2019 and together with Dr Anne he assisted in renewing the Board membership of HAI. He is a chartered accountant.

John O'Connor

Treasurer



John is CEO of The Model County Enterprise Group CLG. Previously, he was a development worker in Makerere University Business School, Uganda. John stayed with Dr Anne for his first four months in Kampala, where he was first introduced to HA. He met his wife Margaret Akot in Uganda and they have four children. He continues to visit Uganda every few years to visit family and HAU.

Úna Ni Rathaille



Úna has recently retired after working as a rural general practitioner in Co Limerick for 24 years. She first met Dr Anne in 1991, when living in Nairobi and working with the Consolata Sisters in Limuru. They worked together for several months, before Anne moved to Uganda to set up HAU. They have kept in contact ever since.

Micheal McGoldrick



Michael worked with Hospice Africa Uganda as a pharmacist from 1995-97. After returning to Ireland he started Hospice Africa Ireland (then called Friends of Hospice Uganda) with Pauline Pierce and some other volunteers. Since 1998 he has worked as a pharmacist with the HSE Addiction Services.

Chair



Adam's connection to HAU began when he lived in Uganda while working for an Irish agri-tech company. During his time in the country, he was President of the Irish Society in Uganda and was involved in organising a number of memorable St Patrick's Day events that raised funds for HAU. Adam became good friends with Dr Anne after he adopted two of her dogs - Paddy and Cleopatra. He is based in North County Dublin where he works with the family-run chartered accountancy firm. Adam also continues to provide consulting services to projects in East Africa.

Phil Molony Secretary



Phil first met Dr Anne while working in education in Mbarara, Uganda. Between 1993-96 they would meet regularly being the first APSO sponsored volunteers in Uganda. Since then, Phil has maintained both a friendship with Dr Anne and a deep interest in the work of HAU. She has particular connections with Mobile Hospice Mbarara, where she visits every few years. Currently, Phil lives in Co Clare.

Siobhán Kennelly



Dr Siobhán Kennelly first met Dr Anne when she took a year out of her postgraduate medical training in 2005 to work as a doctor with the clinical team in Hospice Uganda. She has remained involved with the work of Hospice Africa Ireland through a number of roles in fundraising, advocacy and Board membership since that time. She is a Consultant Geriatrician in Connolly Hospital, Dublin.

Rebekah Merriman



Rebekah is a junior doctor currently working in London, and a relative of Dr Anne. She has visited HAU on multiple occasions, volunteering with the clinical team. She has a real passion for delivering care to marginalised and disadvantaged communities and has been inspired by Dr Anne in her holistic clinical practice.

Patrick Felle

We also welcome Dr Patrick Felle to the HAI board. Patrick is Associatte Dean of Medicine at UCD, and has a long standing connection with HAU. We are. very excited to have him join us!

THE SITUATION IN UGANDA



Following the devastation from the COVID-19 pandemic, the outbreak of Ebola announced in Sept 2022 was very concerning for the people of Uganda. It meant that lock downs, travel bans and social distancing measures were reinforced once more to prevent the spread of the virus. For HAU, this unfortunately resulted in some limitations in services and activities. Overall, 142 confirmed cases were reported, of which 55 died, and 87 recovered. Fortunately, due to an effective and timely response, on 11 Jan 2023, the government declared that the Ebola outbreak was over. All restrictions have now been lifted and services at HAU can continue as planned.

HAU UPDATE: CONTINUING PALLIATIVE CARE

Service delivery at HAU is ongoing and includes home visits, hospital visits, outpatient care, outreaches, community volunteer worker follow up and bereavement support. In January and February 2023, 160 new patients were registered across the three Hospice sites and there were 1,138 patient encounters recorded. Additionally, the clinical team in Kampala have committed to identifying those in need of palliative care services that are living in slum areas. Following a situation analysis, the clinical team commenced an outreach programme in Namuwongo-Kisugu slum this March and there is a further planned outreach in Katanga slum in April 2023.

HIGHLIGHTS FROM OUR NOVEMBER AGM

The 2022 HAI AGM took place on 12th November in in Our Lady's Hospice, Harold's Cross Education Centre, Dublin. It was also streamed on zoom for those who couldn't attend in. person. Thanks to all those who joined, it was a fantastic afternoon with reflections from the HAI team and a brilliant talk from Dr Anne on ageing and the needs of the growing elderly population in Uganda. We also welcomed new board members and appointed our new HAI chair.



READ MORE ABOUT HAU

Guardian Article, March 2023





'It's not just about dying': Uganda's pioneers of palliative care undaunted by huge challenges

If you haven't already, do check out the Guardian article on the work of HAU. This brilliantly written piece by Isabel Choat explores the ongoing issues surrounding lack of access to adequate pain relief that many in Uganda still face.

Emma in Uganda Two cities, 14 Hills, One Nurse



Emma Matthews, a palliative care nurse working at St Luke's Hospice in Sheffield, UK, volunteered with the clinical team in Uganda for 2 months in February and March. Check out her brilliantly written blog about her experiences there!

https://sites.google.com/view/emma-uganda-blog

REFLECTIONS ON THE YEAR 2022: A STORY OF LITTLE HOSPICE HOIMA



Some of the LHH team members and volunteers

The Christmas period brought a surge of activities all the way from September when we celebrate HAU's birthday, October when we celebrate World Hospice and Palliative Care Day, November when we hold an interdenominational memorial service with families of our departed patients, and December when we hold the Patients' Christmas and staff end of year celebration.

In 2022, we held the memorial service "scientifically" due to the Ebola outbreak, as we did the last two years due to the COVID-19 pandemic. It was smaller in size, attended only in-person by the LHH team, choir and clergy. Disease outbreaks disrupt medical services and patients / family members suffer significantly. The memorial service is part of bereavement support for the family members of the deceased to come to their own healing from the grief of losing their loved ones. We prayed for the souls of 101 patients who were enrolled in our care and died during the year. This is a big number, which underlines the fact that many of our patients reach us late Socioeconomic constraints, with terminal disease. usually characterized by poverty and inability to access appropriate care early, is the major cause. Jane's story (see right) is an example of how poverty affects patient outcomes.



Sunday Amos, general assistant at LHH giving a pack of food for Christmas

At Christmas, our patients and their families receive packages containing rice, sugar, soap, maize flour and salt. The end of year season is very special them. We see it on their faces and hear it in their words of excitement when we visit them. The Christmas food packages mean so much to all of them. Thanks to all who give to Comfort fund because they have enabled HAU to maintain this extra service as an integral part of holistic care.

Jane's story

Jane*, 22, was diagnosed with HIV 2021. this early At time. she developed nodular lesions on the left leg, which progressed so fast that by August 2021, she had difficulty walking. At the regional hospital, a doctor advised a biopsy costing \$22, but Jane could not afford this. In July 2022, she came to Little Hospice Hoima for the first time. She was in severe pain and the nodules were foul smelling with ulcerations extending to her groin. She had two children aged 3 and 8 (both not in school), and was pregnant. We enrolled Jane for hospice care that <u>day.</u> We cleaned and treated her her wounds. gave pain relief. contacted her HIV team to ensure she resumed treatment and linked to antenatal services. We her supported her to have the biopsy, which sadly confirmed advanced Kaposi's Sarcoma, an AIDS-related cancer. Jane could not be started on chemotherapy as she was pregnant. She delivered a baby in September. In November 2022, when the LHH clinical team visited Jane at home, they found her 3-month-old baby was being fed on black tea. Through the comfort fund for very needy patients, we gave support towards the baby's milk. Jane died a few weeks later. Her baby is now being taken care of by the grandmother, who is also very poor and receives no support from the child's father. Hospice will continue to give some monthly support through comfort fund for the baby's milk.

*Not her real name

Reflecting on the year in totality, seeing how it has unfolded, moving past the turbulence of the Ebola outbreak and the COVID-19 pandemic, we have a million reasons to be thankful to God. Despite all, we have had many good moments and these have uplifted, re-energized, and rekindled our energy to keep the focus on the mission alive, 'palliative care for all in need'. We were privileged to host the His Excellency. Kevin Colgan, the Irish Ambassador to Uganda accompanied by his team from the Embassy and Adam Sweetman the HAI secretary, presently chair. We hosted Joy Mirembe – the chair Board of HAU, Dr. Kenneth Alfred Kiiza – the Vice Chair Board HAU and one other HAU board member – Rotarian PDG Kenneth Mugisha. We have received regular talks from the founder, Dr. Anne Merriman and these bring motivation to us. And then we attended the HAU AGM, and the HAUK Christmas Quiz. I also, for the first time, attended the HAI AGM. It was great!

We are thankfully and courageously looking forward to 2023.