



Annual Report 2022

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United Kingdom Thalassaemia Society as the secretariat services supports the work of the APPG for thalassaemia and its members by providing logistics and administrative services, arranging meetings, helping draft reports and other documents and ensuring the smooth running of the APPG.

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All-Party Parliamentary Group for thalassaemia

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Foreword



It is my pleasure to present the All-Party Parliamentary Group for thalassaemia annual report for 2022. The work we are doing today is more relevant than ever.

There remains a worrying issue relating to inconsistency of care around the UK and inequalities in accessing new treatments for individuals living with and families affected by thalassaemia. As such, we have been working tirelessly to address these concerns by meeting with key government officials and by hosting events in parliament and around the country to highlight the challenges and advocate for change. Please see the report for the activities which took place during the period of January 2022-September 2022.

2022/2023 is set to be another hectic year for us. We look forward to working further on the many initiatives suggested by the thalassaemia community to deliver the best and most helpful services, resources and events which will truly benefit them.

Outstanding patient experience and access to quality care remains our utmost priority.

Lastly, I would like to extend my sincere thanks to the thalassaemia community and my fellow committee members for your continued resilience, interaction, dedication, and support to thalassaemia. Your example remains a wonderful source of inspiration and motivation for us, and it is a great honour for me to be leading the APPG for thalassaemia.

Every one of us has an important role to play in the work ahead and I'm confident that together we will achieve great things.

I look forward to being able to interact and celebrate the rest of activities planned with you, continuing our collective collaboration in promoting awareness, education, training, research, and most of all in supporting for all individuals living with, affected by, or working in thalassaemia.

A handwritten signature in green ink that reads "Bambos". The script is cursive and fluid.

Bambos Charalambous MP for Southgate and Chair of the APPG for thalassaemia

APPG on thalassaemia Committee Members

The APPG for thalassaemia has around 9 committee members. See table below.

| | | |
|------------|---------------------|----------------|
| CHAIR | BAMBOS CHARALAMBOUS | LABOUR |
| VICE CHAIR | MIKE WOOD MP | CONSERVATIVE |
| VICE CHAIR | BOB BLACKMAN MP | CONSERVATIVE |
| VICE CHAIR | KATE OSAMOR MP | LABOUR (CO-OP) |
| VICE CHAIR | FABIAN HAMILTON MP | LABOUR |
| VICE CHAIR | CATHERINE WEST MP | LABOUR |
| VICE CHAIR | TAIWO OWATEMI MP | LABOUR |
| VICE CHAIR | FERYAL CLARK MP | LABOUR |
| VICE CHAIR | ABENA OPPONG- ASARE | LABOUR |

APPG for thalassaemia

All-Party Parliamentary Groups (APPGs) are informal cross-party groups that have no official status within Parliament. They are run by and for Members of the Commons and Lords, though many choose to involve individuals and organisations from outside Parliament in their administration and activities.

Our APPG group for thalassaemia aims to raise awareness of this rare condition and encourage policy changes to improve services, quality of life and survival rates for people living with a form of thalassaemia.

We hope to do this by educating and encouraging Members of Parliament achieve this aim by engaging with parliamentary colleagues, the government and health professionals to raise awareness relating to the conditions and needs of patients.

Frequent meetings will be carried out to discuss upcoming plans, raising issues in thalassaemia and other important topics to ensure we are ready to debate with members of parliament.

We also have an **annual general meeting** (AGM) which is a yearly gathering between the shareholders of the UKTS, members of the UKTS and its board of directors. The aim of the **AGM** is to provide the trustees and/or officers the opportunity to explain their management of the **charity** or organisation to the members. It also provides the members with an opportunity to ask questions before voting on business items on the agenda.

Aims and Objectives

Our upcoming plans that we intend to address this year includes:

1. Tackling the inequalities and inconsistencies within services that people with thalassaemia face across the UK.
2. Highlighting the issues that individuals living with thalassaemia face when applying to the DWP for Personal Independent Payment.
3. Shining a light on the unfair process that the rare disease community faces during Technology Appraisals.
4. Addressing the unfairness of Prescription Charges for adults with thalassaemia

Parliamentary Activities

January 19th 2022

Annual general meeting was held. Committee members and other members of parliament were briefed on some of the challenges facing the thalassaemia community.

March 29th 2022



UKTS Trustee, Roanna Maharaj attended a round table discussion on rare diseases chaired by the Rt Hon Sajid Javid MP, Secretary of State for Health & Social Care at the Zayed Centre for Research, Great Ormond Street, to discuss health disparities & research/innovation.

Some of the other attendees present were:

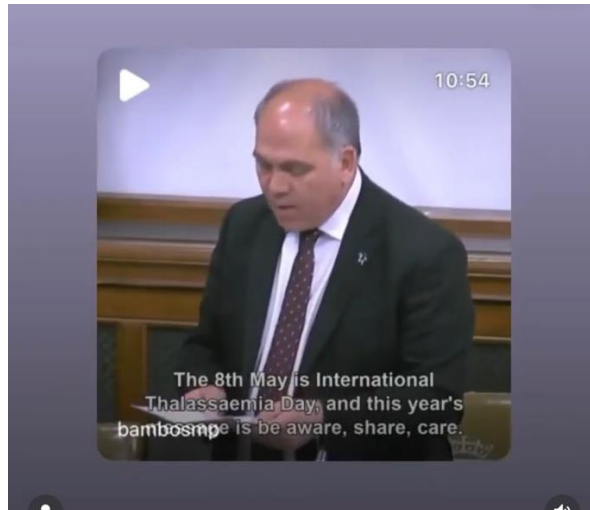
- Richard Scott, Chief Medical Officer at Genomic England (pictured)
- Derralyn Hughes (professor of experimental haematology)
- Claire Booth (professor in Gene Therapy and Paediatric Immunology)
- Matthew Shaw (CEO of Gosh)

Roanna was given the chance to highlight thalassaemia and some of the problems our community is currently facing in the UK – such as the inequalities in accessing quality thalassaemia care and potentially curative therapies, the new-born screening programme and the lack of resources/support available to our families.

May 8th 2022

International Thalassaemia Day

Westminster Debate



Bambos Charalambous MP, Chair of the All-Party Parliamentary Group for thalassaemia, delivered a debate in parliament ahead of 8 May. He called on the government to raise awareness about thalassaemia among health professionals and the wider public to improve health outcomes for the people with Thalassaemia. Bambos highlighted some of the challenges faced by the thalassaemia community, referring to some cases of racism and below standard treatment some patients experienced based on their ethnicity throughout the country.

UKTS FUN RUN/WALK



Bambos Charalambous MP participated in the UKTS event in Southgate to raise awareness of thalassaemia to the local community and advocate for change. Bambos also did a few live radio interviews on London Greek Radio (LGR) to highlight the importance of early screening for thalassaemia, the need for blood donation and the importance for the community to have access to new treatments.

June 8th 2022



Gabriel Theophanous (UKTS Chair), Romaine Maharaj (UKTS Executive Director) and Roanna Maharaj (UKTS Trustee) met with Bambos Charalambous MP for Southgate and Chair of the All Party Group for thalassaemia in Westminster to discuss issues affecting our thalassaemia community and upcoming campaigns and events on our political agenda.

July 14th 2022



Bambos Charalambous MP and Chair of the All Party Parliamentary Group for thalassaemia hosted an event at the House of Commons to discuss critical issues affecting the thalassaemia community.

Together, the group identified 4 key areas to tackle & began planning the APPG's next steps. Some of our plans include parliamentary debates, PM questions, follow up with Health Education England. The discussions were extremely helpful, productive and thought provoking!

List of attendees

Members of Parliament:

- Liz Twist MP - Blaydon and Chair of APPG on (Chair of APPG on Rare, Genetic and Undiagnosed Conditions)
- Naz Shah MP - Bradford West
- Paulette Hamilton MP - Birmingham Erdington

Other Attendees

- Kurdistan Regional Government High Representative Karwan Tahir
- NHS Sickle Cell and Thalassaemia Screening programme manager, Amanda Hogan

Patrons

Peter Polycarpou
Kypros Kyprianou

UKTS team

Gabriel Theophanous (Chair)
Romaine Maharaj (Executive Director)
Oddy Cooper (Vice- Chair)
Roanna Maharaj (Vice- Chair)

October 19th 2022

National Thalassaemia Day

Awareness Campaign



Bambos Charalambous MP and other MPs supported UKTS on National Thalassaemia Day and raising awareness of Thalassaemia in Parliament. This also served to educate some of the members on the condition and the need for proper awareness campaigns.



