

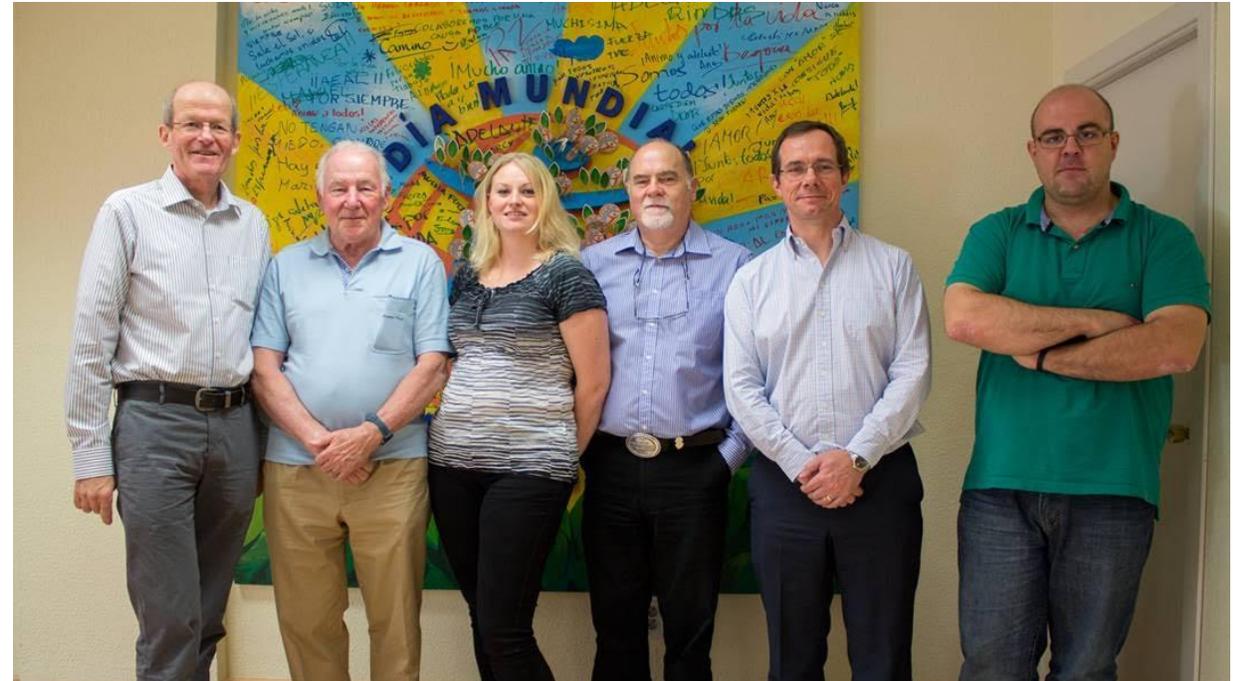
# MPN Advocates Network

## Update

Jon Mathias

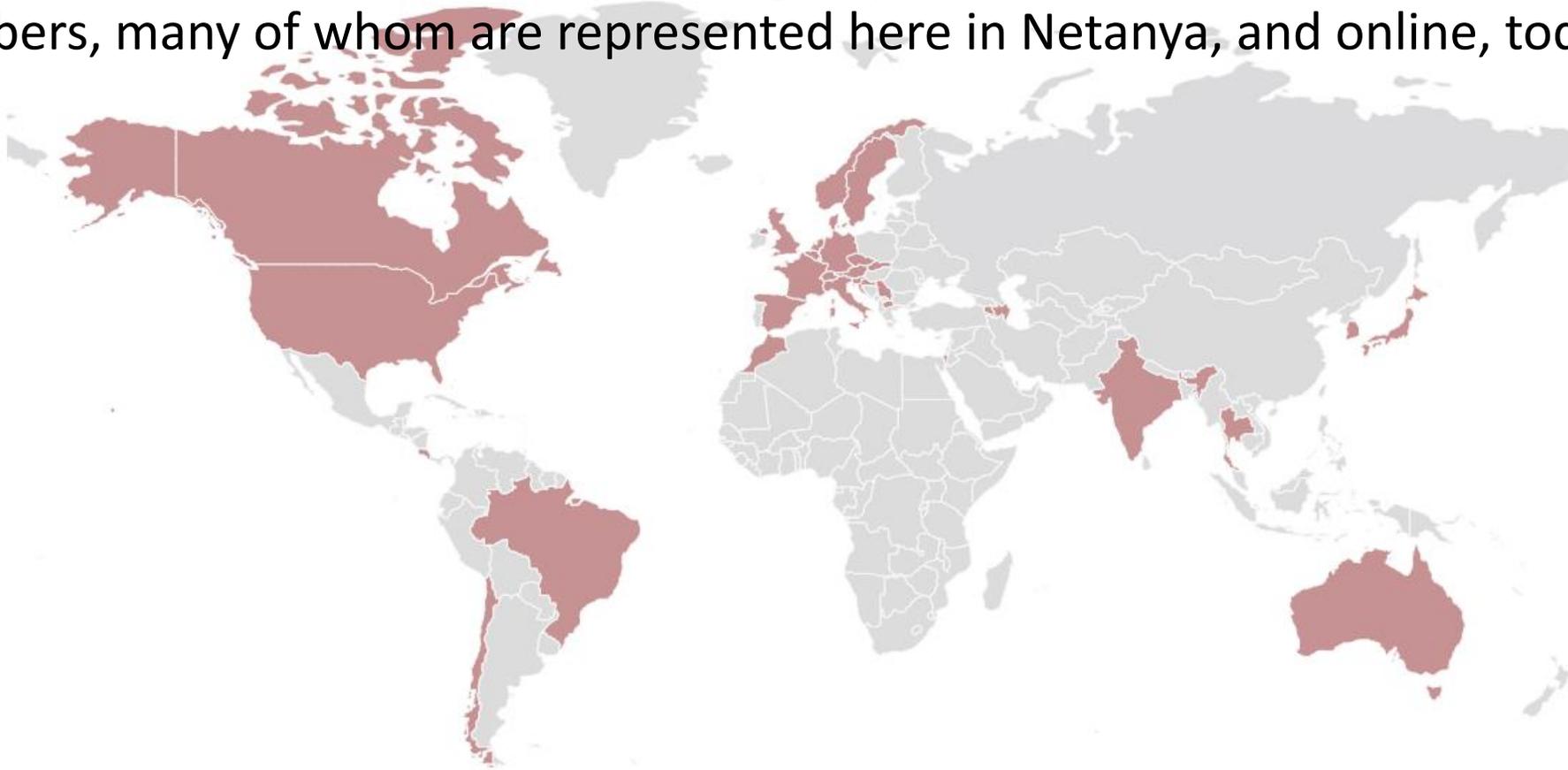
# Origins

- I was diagnosed with ET in 1998 and, since then, have been lucky to be under the care of Professor Claire Harrison and her team at Guy's hospital in London. Claire and a small group of her patients helped to build the MPN Patient Community in the UK, now based around MPN Voice, which has been running for nearly 20 years
- In 2012, Claire emailed me to tell me about a couple of patients in the Netherlands and Spain who were interested in working with other patient groups. Those patients were Frans Pross and Peter Loffelhardt
- In 2013 we formally founded MPN Advocates Network, initially as an independent non-profit in Spain, but subsequently we became a part of the Leukaemia Patient Advocates Foundation (LePAF) which gave us the benefit of an existing registration in Switzerland and provides regulatory and accounting functions.
- We operate alongside 3 'sister' networks who all live under the LePAF umbrella
- We held our first MPN Horizons conference in Belgrade in 2016



# MPNAN Development

From 2013, when there were 3 patient groups in the network, we now have over 40 members, many of whom are represented here in Netanya, and online, today



# Mission and Objectives

While we are pleased that the network has grown, and that we are connected to patient communities all over the world, a patient who is diagnosed with an MPN in 2022 in many parts of the world will be facing an uncertain future alone

So our mission is simple, but ambitious. We want MPN patients, wherever they live, to have access to the the support and information they need to live well with their MPN

We aim to help advocates build and develop patient support groups by sharing information about the diseases and their treatment, and by sharing best practices from our members



# The MPN Landscape in 2022

- Compared to when I was diagnosed in 1998, seven years before the JAK2 mutation was discovered, the MPN Landscape is transformed
- Over the next few days, you will learn about many new avenues of research, and therapies being trialled, which give us the hope of making all MPNs a condition we can expect to live a normal life with
- While medical research has accelerated rapidly over the past 20 years, and has delivered life-changing drugs, living with an MPN is still a huge burden for many patients



For those of us who have chosen to support and advocate for MPN patients, there is still a lot to do, and I hope this conference will help and inspire you all to do that