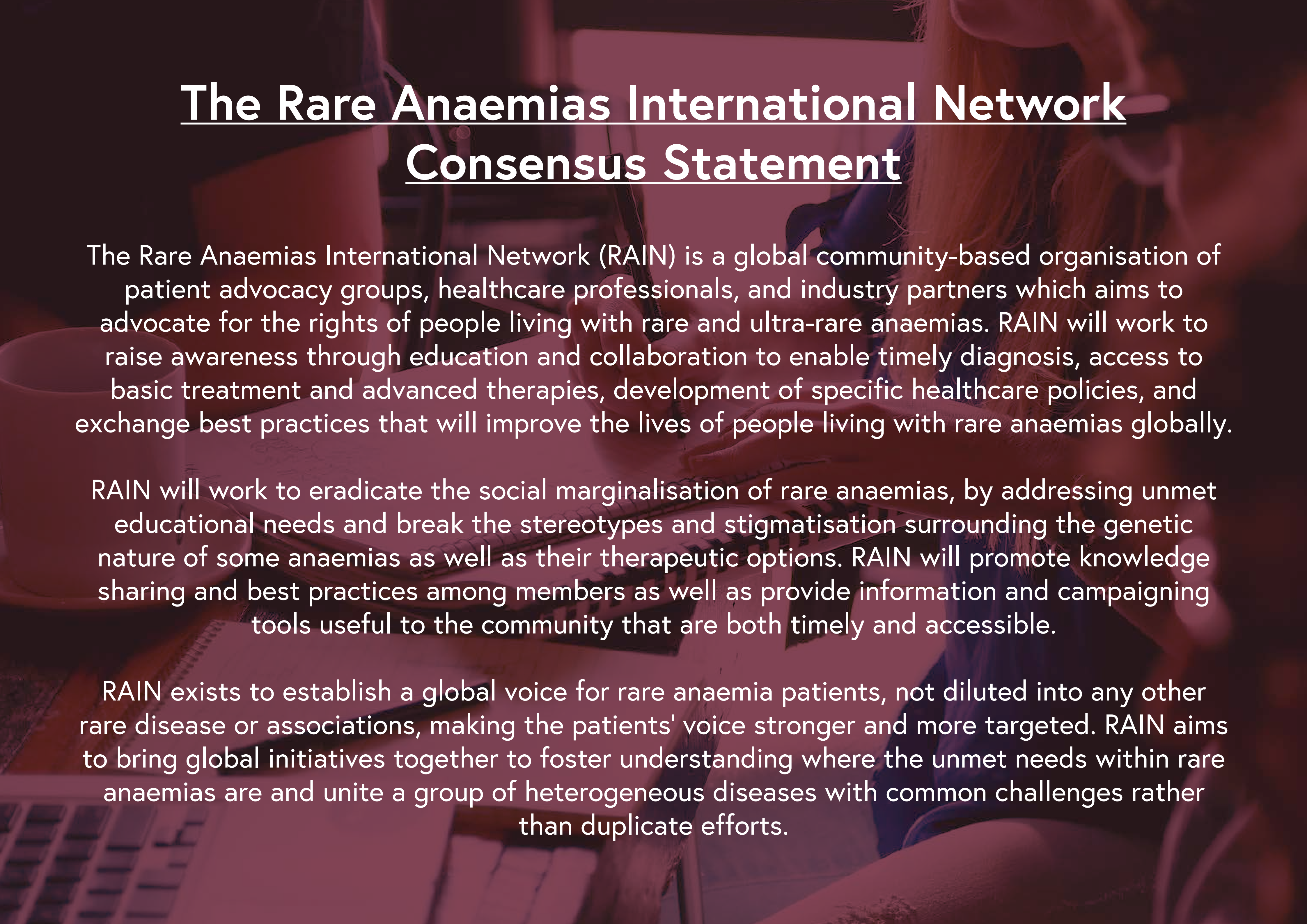

The Rare Anaemias International Network Consensus Statement

The Rare Anaemias International Network (RAIN) is a global community-based organisation of patient advocacy groups, healthcare professionals, and industry partners which aims to advocate for the rights of people living with rare and ultra-rare anaemias. RAIN will work to raise awareness through education and collaboration to enable timely diagnosis, access to basic treatment and advanced therapies, development of specific healthcare policies, and exchange best practices that will improve the lives of people living with rare anaemias globally.

RAIN will work to eradicate the social marginalisation of rare anaemias, by addressing unmet educational needs and break the stereotypes and stigmatisation surrounding the genetic nature of some anaemias as well as their therapeutic options. RAIN will promote knowledge sharing and best practices among members as well as provide information and campaigning tools useful to the community that are both timely and accessible.

RAIN exists to establish a global voice for rare anaemia patients, not diluted into any other rare disease or associations, making the patients' voice stronger and more targeted. RAIN aims to bring global initiatives together to foster understanding where the unmet needs within rare anaemias are and unite a group of heterogeneous diseases with common challenges rather than duplicate efforts.