

**An international declaration  
published by the Global GIST Community  
to promote access to state-of-the-art GIST treatment and care  
for all patients, wherever they may live.**

**1st of July 2007**

**Developed, agreed and signed  
by representatives of worldwide GIST Patient Advocacy Groups  
during an international conference  
from the 29th of June until the 1st of July 2007 in Bad Nauheim, Germany.**

## The Declaration: Background Statement

1. Gastrointestinal stromal tumour (GIST) is a rare cancer of the mesenchymal (connective) tissues of the stomach, gastrointestinal tract and related organs. The incidence of this cancer is approximately 12 -15 per million of population, and it is regarded as a rare disease. It accounts for less than one half of one percent of all cancers diagnosed.
2. In the early years of the 21st century the treatment of GIST was revolutionised by the introduction of tyrosine kinase inhibitors. Prior to their introduction a patient diagnosed with advanced GIST had a life expectancy of less than two years. With tyrosine kinase inhibitors (e.g. imatinib for first-line therapy) the prognosis of patients has improved significantly. Over 85% of patients respond to these drugs and benefit for many years.

## The Declaration: Purpose

1. The worldwide advocacy groups supporting patients with GIST are all concerned about the differences that exist in the way in which patients are treated, and the ways in which healthcare systems often delay access to new treatments.
2. We believe that all patients should be treated equally regardless of race, nationality, faith, age, sex or economic status.
3. This document is a consensus Declaration from the GIST patient advocacy groups assembled at Bad Nauheim, Germany on Sunday 1st July 2007. It identifies a set of basic standards which we call on doctors, other health care practitioners, hospital administrators and health care funders to adopt and to build upon for the benefit of the patients they serve.
4. The global GIST patient advocacy groups will monitor the implementation of this declaration and publicise the healthcare systems demonstrating adherence to it.








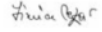









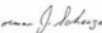

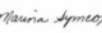



## The Declaration

*The undersigned GIST patient advocacy groups collectively call on all those responsible for the treatment and care of patients with gastrointestinal stromal tumour (GIST) to:*

1. Ensure that patients are diagnosed promptly and accurately
2. Provide the information and resources which allow patients access to specialist second opinions
3. Provide treatment and care to GIST patients through the hands of specialist multi-disciplinary teams which conform to standards for a centre of expertise in rare diseases (see note). All members of these teams should have specialist knowledge, continuing experience of treating GIST, and participate in national and/or international networking with other centres of expertise.

4. Provide access to expert pathology and mutation analysis services which give doctors and patients the information they need to make an informed clinical decision.
5. Provide accurate and timely information relevant to the patient at each step along the treatment pathway
6. Provide access to psychological support and treatment
7. Adopt an internationally accepted treatment guideline (see 8 below) and ensure that the resources required to deliver it are available to doctors and patients
8. Treat patients in line with an internationally accepted treatment guideline (see note) informed by the published evidence from scientific and clinical research
9. Maintain and review funding for treatment so that no patient suffers through failure to treat, or through stopping treatment recommended by specialist doctors
10. Provide patients with access to clinical trials regardless of race, nationality, faith, age, sex or economic status.

**Signed in Bad Nauheim, Germany - Sunday 1st July 2007**

Kris Heyman	Contactgroup GIST - Belgien		Stanislaw Kulisz	GIST Patient Association Poland	
Daniel Josephy	Life Raft Group Canada		Aisha Ou	GIST Patient Association Poland	
Estelle Lecointe	A.F.P.G. - Ensemble contre le GIST		Simona Ene	Romania GIST Network	
Markus Wartenberg	Das Lebenshaus e.V. - GIST		Cezar Irimia	Romania GIST Network	
Judith Robinson	GIST Support UK		Ulrich Schnorf	Das Lebenshaus e.V. Schweiz	
David Robinson	GIST Support UK		Hilbrand Bruinsma	Contactgroup GIST Nederland	
Roger Wilson	Sarcoma UK		Ton De Keijser	Contactgroup GIST Nederland	
Tunde Kazda	CML es GIST betegék egyesülete		Carolin Verhoogt-de Vries	Contactgroup GIST Nederland	
Reuven Halfi	Israel GIST Group		Norman Scherzer	Life Raft Group USA	
Anna Costato	Associazione Italiana GIST - A.I.G.		Marina Symcox	GSI - GIST Support International	
Jan-Einar Moe	Life Raft Group Norway		Kai Pilgermann	Das Lebenshaus e.V. - GIST	
			Stefanie Peyk	Das Lebenshaus e.V. - GIST	

**Note to 3.** An example of standards for a Centre of Excellence is given by the European Union in its report on Networks of Reference for Rare Diseases which can be found at [http://ec.europa.eu/health/ph\\_threats/non\\_com/rare\\_8\\_en.htm#1](http://ec.europa.eu/health/ph_threats/non_com/rare_8_en.htm#1)

**Note to 8.** An example guideline is offered by the National Comprehensive Cancer Network (NCCN). You will find the NCCN-Guidelines for GIST (Soft Tissue Sarcoma) as PDF file at [http://www.nccn.org/professionals/physician\\_gls/](http://www.nccn.org/professionals/physician_gls/)