

EU Thalidomide Survivors' Campaign : Press Pack

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The EU Campaign Team is calling on the German Government to render financial assistance to the dwindling number of Thalidomide survivors in Italy, Spain, Sweden and the United Kingdom.

It is clear that the original Settlement reached in Germany between the manufacturer, Grunenthal, and the then German Government was wholly inadequate and the process was significantly flawed.

There is increasing support from across Europe for the present German Government to put right this historic injustice and ease the physical suffering of the remaining survivors before it is too late.

1) Introduction

1.1. EU Thalidomide survivors need urgent humanitarian financial help to finally ensure their health and independent living costs will be met, after over 50 years of under, or even in many cases, zero funding. The cost of delay is measured in the loss of dignity, significantly deteriorating health and the ongoing daily pain and suffering of the victims and their families. It is not simply measured in Euros.

1.2. Whilst there may be some legal issues, this is universally recognised as a political matter.

1.3. We welcome the support of the EU Parliament, which is speaking with one voice, in calling on Chancellor Merkel to ensure the German Federal Government sits down with each country's campaign team in the German Embassy in each respective capital.

2) Background

2.1. Thalidomide was used in the late 1950s and early 1960s as a "wonder drug" to treat morning sickness, headaches, coughs, insomnia and colds. Thalidomide was marketed in different countries under different names and advertisements emphasised the drug's complete safety, using phrases such as "non-toxic" and "no known toxicity".

2.2. These claims were untrue and demonstrably known to be so at the time they were made.

2.3. There was a lack of pharmaceutical surveillance. The criminal trial of the German manufacturer was prematurely ended in 1970 with the active participation and encouragement of the German Federal Government. This had the direct effect of suppressing all the evidence preventing the victims obtaining justice in their own countries.

3) Evidence

3.1. Over several years, extensive research of archives has uncovered the truth. The evidence has been independently verified by leading international, commercial lawyers, Ince & Co. We attach a copy of their advice letter, dated 5th March for your information.

3.2. It is clear that the way the Thalidomide disaster was handled, at the time, by the German Federal Government, fell far below its usual high standards.

3.3. In the light of the new compelling evidence, and in the modern era of transparency and accountability, there is an opportunity for Germany to accept her moral responsibilities and act swiftly on humanitarian grounds, to bring much needed relief and assistance to Thalidomide survivors.

4) Health Deterioration of Thalidomide Survivors

4.1. The evidence of the exponential deterioration in health is overwhelming.

4.2. In recent years, there have been many reports, from different countries, investigating the health of Thalidomide survivors. Some were based on interviews with and assessment of the victims themselves whilst others drew on detailed medical records and responses from their doctors. From Germany, we have the University of Heidelberg and Cologne Reports. There is a major Report from Canada and from the United Kingdom we have the Firefly and Securing Our Future Reports.

4.3. As an example, consider SF12 which is a widely used health survey to measure health-related quality of life. In the United Kingdom, a controlled survey found that Thalidomide survivors were in the bottom 2% of the general population with the poorest health related quality of life. In addition, their health is worse than post stroke patients and MS (Multiple Sclerosis) sufferers, 10 years after the onset of symptoms. The results would be similar in Sweden and probably worse in Italy & Spain, of course, as they have received so much less, and in many cases zero, funding to help reduce their deterioration in health.

4.4. Consider the Thalidomide child with no arms who was taught, and learned to improvise, to be independent. To write, eat, drink, dress and even brush their hair using their feet. This over, and inappropriate, use of their legs has led to operations to replace knee joints, totally disabling the formerly partially independent adult.

4.5. The majority of Thalidomide survivors live with constant pain and require pain relief; many necessitating analgesics.

4.6. Many EU Thalidomide survivors have been cared for by their parents for their whole lives. Unfortunately, these elderly parents are now in need of care themselves, or have died, creating enormous practical, physical and emotional problems.

5) The Solution

5.1. The vast majority of victims are beyond the help of human agents. There is a shared responsibility, to help the survivors, between all the guilty parties; the German manufacturer (Grünenthal) the distributors (where they still exist), the national Governments and the German Federal Government.

5.2. We are only looking for quantifiable funding to cover real tangible costs.

5.3. The number of EU Thalidomide survivors receiving no assistance from Germany is not high at probably less than 1,000 and they continue to fall in number. The costs of meeting their needs are de minimis to the German Federal Government and will fall each year to zero eventually.

5.4. For example, in the UK there are currently just 468 Thalidomide survivors and various Reports show they need only GBP10m (E14m) in year 1 to cover their unmet needs.

5.5. Each country has very different circumstances. We recommend that, as a matter of urgency, Germany immediately invites each representative Group to a meeting, at ministerial level, with a view to finally going through a process of 'truth & restitution' after over 50 years. These meetings should be held at her Embassy, in each country, on the grounds of efficiency and practical issues for Thalidomide impaired negotiators.

6) Political Support

6.1. The EU Campaign enjoys the full support of the EU Parliament. Campaigners have met hundreds of MEPs and walked or wheeled around to knock on almost every MEP's door over the last 17 months.

6.2. All 7 Group Presidents have written to Chancellor Merkel urging her Government to meet with us and look at our case sympathetically.

6.3. The EU Campaign Team enjoyed a very positive meeting with EU Parliament President Schulz on 5th May.

6.4. The EU Commission is celebrating the 50th Anniversary of the First EU Pharmaceutical Legislation, this year, which was heavily motivated by the Thalidomide disaster. We have contributed to the Commemorative Booklet and have been invited to address the Event on 28th September 2015.

6.5. Independent observers might suggest it is ironic that those victims, whose (ongoing) pain and suffering prompted such positive Legislation, which has protected and benefitted millions of European citizens, have still not received justice.

7) Summary

7.1. We are a unique group, in a unique position requiring a unique solution.

7.2. The EU is “founded on the values of respect for human dignity, freedom, democracy, equality, the rule of law and respect for human rights.”

7.3. This year is the right time to finally do the right thing for EU Thalidomide survivors and the EU is exactly the right Institution to assist in this process. We would like to thank and congratulate the EU Parliament for speaking with one voice in support for our search for justice, so that EU thalidomide survivors can live out the remaining years of their lives in less pain, and with more dignity than they have over the past 50 years.

7.3 We look forward to hearing from Chancellor Merkel and Manuela Schwesig, Federal Minister of Family Affairs, Senior Citizens, Women and Youth in the near future.

www.fiftyyearfight.org