

Institution: University of Glasgow (UofG)

Unit of Assessment: 28 History

Title of case study: Thalidomide: maintaining a public profile in the pursuit of justice

Period when the underpinning research was undertaken: 2009–2018

Details of staff conducting the underpinning research from the submitting unit:

Name(s):

Role(s) (e.g. job title):

Period(s) employed by submitting HEI:

Ray Stokes

Chair of Business History

1995-present

Period when the claimed impact occurred: 1st August 2013–31st July 2020

Is this case study continued from a case study submitted in 2014? N

1. Summary of the impact

UofG research has been instrumental in increasing public recognition of the role of German company Chemie Grünenthal (CG) in the thalidomide scandal and its aftermath. Exposure of the full extent of CG's culpability, as well as the complicity of the German federal and state governments, has re-ignited campaigns for thalidomide victims in the UK, Australia and beyond. Stokes together with his collaborators have since 2013 refocused public attention onto this injustice, including CG's role and the suspension of the trial of company executives in 1970. This has led to demands for a German government inquiry, more sustainable levels of support for thalidomide survivors in the UK and in other countries, and a unanimous resolution passed by the European Parliament in 2016.

2. Underpinning research

The thalidomide catastrophe affected large numbers of children in developed countries from the late 1950s until November 1961, 8–9 months after its withdrawal from sale in most countries. Images of these children, many with shortened limbs or other visible birth defects, abound in the popular media. This catastrophe led to much more effective clinical testing, regulation and legislation for medicines, and there is a considerable scholarly and popular literature on various of its aspects.

Still, despite sustained attention to thalidomide by scholars and the media over several decades, a comprehensive historical account of the drug was lacking until the mid-2018 publication of a book, researched 2010–2018 by Stokes and his co-authors from the third sector. The research utilises newly available sources, and provides the first full account of the history of this devastating drug from its origins to the present: critically examining the drug's origins, its makers and marketers; its victims; its withdrawal from sale in most countries; the trial and the circumstances surrounding its suspension; continuing campaigns for justice; and the drug's continued impact on people worldwide even after 'withdrawal' in 1961.

Key findings include:

- Stokes examined documents produced following the withdrawal of thalidomide pending criminal trial of CG executives, many never used previously by researchers, providing new evidence of the true extent of the company's misbehaviour between 1954-1961.
- Stokes and his collaborators produced estimates of the full extent of the thalidomide catastrophe, including stillbirths and miscarriages as well as survivors, by country; crucially, they estimated how many deaths and injuries could have been avoided, had the drug been withdrawn earlier than autumn 1961 in response to credible and numerous requests starting in 1958.
- The West German government worked closely with the state of North Rhine Westphalia's
 Justice Ministry as well as with CG and its attorneys but crucially not with the families



directly affected by the catastrophe – to establish the framework and resources for an eventual paltry settlement offer to survivors in Germany. They did this knowing that it represented at best 10% of legitimate claims. Importantly, these powerful men and organisations together engineered the suspension of the trial, against official advice that this was almost certainly unlawful, and probably unconstitutional. The settlement and the trial's suspension were inextricably related, even though settling a criminal trial through a financial settlement was not at that time legal in Germany.

One of the most unexpected and significant research findings was evidence of CG's continuing role after 1961 in the development and production of thalidomide. The catastrophe of the late 1950s and early 1960s did not stop this firm – and later others – from continuing to market, distribute and develop the drug, seeking new uses for it into the 21st century. There remain questions over how CG benefited from this 40-year programme of work following the drug's withdrawal in 1961, which led directly to a 2nd-generation thalidomide disaster in the past decade, mainly centred in Brazil.

Professor Stokes's central contribution to this research included evaluation of historical evidence and rewriting and editing the contributions of co-authors for scholarly integrity. He also carried out historical research into the criminal trial of CG executives, and the German Government's problematic involvement in arranging that trial to be suspended. Stokes's contributions to the project and its impact were informed by his knowledge from his wider, decades-long body of work on 20th century German chemical and pharmaceutical industry, which uniquely combines business, economic and technological history, and has placed the research in appropriate historical context [e.g. 3.2–3.6].

3. References to the research

- 3.1 Johnson, M., Stokes, R. G. and Arndt, T. 2018. *The Thalidomide Catastrophe: How it Happened, who was Responsible and why the Search for Justice Continues after More than Six Decades*. Onwards & Upwards: Exeter. [available on request from HEI]
- 3.2 Stokes, R. 2014. <u>Das politische und technische Erbe der IG Farbenindustrie AG in Mitteldeutschland.</u> In: Karlsch, R. and Maier, H. (eds.) *Studien zur Geschichte der Filmfabriken Wolfen und der IG Farbenindustrie AG in Mitteldeutschland.* Series: Bochumer Studien zur Technik- und Umweltgeschichte (2). Klartext: Bochum, pp. 39–53. [available on request from HEI]
- 3.3 Stokes, R. 2008. Research and development in German industry in the Nazi period: motivations and incentives, directions, outcomes. In: Buchheim, C. (ed.) German Industry in the Nazi Period. Series: Vierteljahrschrift für Sozial- und Wirtschaftsgeschichte (174/3). Franz Steiner Verlag, pp. 199–211. [available on request from HEI]
- 3.4 Abelshauser, W., Von Hippel, W., Johnson, J.A. and <u>Stokes, R.G.</u> 2004. *German Industry and Global Enterprise. BASF: the History of a Company.* Cambridge University Press. [available on request from HEI]
- 3.5 Stokes, R. 1988 (2nd ed. 2009) *Divide and Prosper: The Heirs of IG Farben under Allied Authority, 1945–1951*. University of California Press; 2nd ed. Hexagon Press. [available on request from HEI]

Quality: The key work, 3.1, is based on rigorous and original research and expected to meet or exceed the 2* threshold. Other items in the body of work are of similar quality and all are peer-reviewed.



4. Details of the impact

Worldwide, ~123,000 babies are thought to have been stillborn or miscarried due to thalidomide, and 24,000 more were born with thalidomide-induced birth defects [link]. Approximately 5,000 thalidomide survivors worldwide today form a well-connected community, with very strong links between the German and British 'thalidomiders' (a term of self-identification) and others in NW Europe. Despite the time elapsed, there remains a need for further justice, not least because survivors, born mostly in late 1950s–early 1960s, are aging, and their disabilities have caused their needs to increase substantially over the years. The research has contributed to raising and maintaining awareness of this important issue.

The research came about through Stokes' collaborations with Dr Martin Johnson, director of UK Thalidomide Trust for 13 years until his recent retirement; Tobias Arndt, a Brussels-based researcher and director of EDRIC (formerly the European Dysmelia Reference Information Centre, now DysNet); and Sir Harold Evans, a journalist and long-time campaigner for thalidomide justice. Johnson [5.1] stated that 'by 2009 it was clear that we needed an expert historian, and [one] with a facility in the German language' adding that Stokes' contribution was 'key to finding, analysing, and presenting the information in a comprehensible and effective way'. Reflecting this, Evans described the research as 'carry[ing] conviction by its scientific rigor, its energy in tracking evidence, its restraint in reaching conclusions and the cool clarity of the writing' [5.2].

Keeping thalidomide and lessons learned in the public consciousness

While the research was ongoing and prior to its publication as a book [3.1], Stokes and collaborators engaged keenly with the media, leading to widespread coverage [5.4]. The issue was, for example, covered in the <u>Guardian</u> in November 2014, <u>Reuters</u> in November 2014, the <u>Guardian</u> in March 2016. The <u>Guardian</u> in December 2014 covered the struggles of Spanish campaigners for equal compensation to that received by thalidomiders in other European countries. Among the reviews when the book was released in 2018, the London Evening Standard noted that 'Piece by piece the authors have put together a grim jigsaw that the family owners of Grünenthal hoped would never see the light of day ... a thorough and painstaking attempt ... to document the lies that have denied justice to thousands' [5.3].

Documentary films in the UK, Canada and Germany drew on the research, helping keep thalidomide in the public consciousness. For example, Stokes was interviewed extensively in 2016 for the podcast <u>BBC Witness: the thalidomide trial</u> (broadcast 29 May 2018). The research also reached the public via a 2016 Canadian Broadcasting Company documentary <u>No Limits:</u> <u>The Thalidomide Story</u> and a German documentary film by Westdeutsche Rundfunk, which aired in September 2016 including interviews with Stokes and his co-authors.

Supporting campaigns for political awareness, justice and compensation

The release of preliminary research findings in 2014 generated media interest [5.4] that supported activities of major thalidomide advocacy organisations and influential individuals, and maintained pressure on thalidomide manufacturers and governments. The campaign website Fifty Year Fight [5.5] also used material from the research. All royalties from the book are donated to DysNet, who are also sharing the research with thalidomiders.

The research has also supported activists to win additional compensation from the British government as well as from Diageo in the UK. (Diageo is the legal successor to The Distillers Company, the British and Commonwealth thalidomide licensee of CG.) There has also been



additional compensation from Diageo in Australia [5.5], where Stokes and his collaborators helped the legal team in Australia prepare their case, providing documents and context. The lawsuit was settled in 2014 [5.5], resulting in additional compensation for thalidomide survivors, including a number who were newly identified.

In November 2014 a formal question was raised and debated in the European Parliament, followed by a unanimous resolution in 2016, resulting from work by activists using documents discovered by Stokes and his co-authors. According to two key campaigners [5.6] Stokes' work was used by the lawyers in producing a legal opinion in 2015 which suggested that 'the German Federal President and five German government departments acted illegally by interfering in a criminal trial'. They added:

this legal opinion formed the basis for a campaign in the European Parliament which culminated in a Resolution passed in December 2016, calling on the German Government to ensure all survivors' health needs are adequately funded.

Coverage of the culpability of the German government and Chemie Grünenthal, one of the key issues in the book, appeared in the <u>Sunday Times</u> (29 April 2018) prior to the book's imminent publication, leading directly on 2 May to a question being asked of the Prime Minister in the UK parliament by Simon Hoare MP [5.7]. The then Prime Minister responded that her minister for Europe and the Americas was meeting with representatives of the Thalidomide Trust to discuss the news, and the Foreign and Commonwealth Office is remaining in contact with the trust and pursuing discussions with the German Government [5.7]. A further <u>written question</u> was raised in June 2018 by MP Royston Smith.

Impact on the thalidomide-affected community

In September 2019, the Scottish Parliament hosted an event organised by a Scottish thalidomider and sponsored by MSPs Ruth Maguire and Linda Fabiani, described as 'a celebration of the lives of thalidomide survivors and families'. Scottish thalidomiders and their families attended, and as the event was focused on the book Stokes and Martin Johnson were invited to speak about the research. According to the Secretary to the Board of Trustees of the Thalidomide Society, Stokes has 'opened out the many opaque and hidden aspects of the German historical documents' and 'made them accessible to the thalidomide community, without losing their complexity' [5.8]. The Secretary added:

This access has been widely acknowledged and appreciated by Society members, many of whom have purchased a copy of the book. Some answers, at last! There is no price to put on the value of clear explanation and analysis for thalidomide survivors — an end to a lifetime of wondering and speculation as well as a way of explaining the origins of their impairments to family, doctors and strangers.

5. Sources to corroborate the impact

- 5.1 Testimonial letter, UK Thalidomide Trust: former head Dr Martin Johnson, collaborator and disseminator of the research [PDF], explaining the importance of Stokes' academic contributions to their collaboration as well as details of the impact of the work.
- 5.2 Foreword to the book by Sir Harold Evans, former editor of *The Times*, campaigner for thalidomide justice, who covered the CG trial in high-profile media outlets [PDF], detailing the origin and nature of the collaboration that produced the book including the importance of the historical rigour brought by Stokes.
- 5.3 Book <u>review</u> in the London Evening Standard 5 July 2018 [PDF], exemplifying media coverage and showing the depth of awareness brought by the book.



- 5.4 Media coverage, in particular via *The Guardian* and *The Times* about the ongoing campaigns to make Grünenthal accountable. [combined PDF]:
 - a. Guardian: how men who blighted lives of thousands evaded justice (Nov 2014)
 - b. Reuters: questions about thalidomide criminal trial (Nov 2014)
 - c. Guardian: interview with Martin Johnson of Thalidomide Trust (March 2016)
 - d. Guardian: Spanish resistance court decision against compensation (Dec 2014)
- 5.5 Coverage of compensation stories [PDF], again highlighting the increase in public awareness achieved by the research:
 - a. https://www.theaustralian.com.au/news/nation/thalidomide-victim-lynette-rowe-compensated-for-life-after-distributor-settlement/news-story/dd035eb8e2dc9e02623678b0dad5a27d
 - b. https://www.theguardian.com/society/2014/feb/07/thalidomide-victims-receive-89m-compensation
 - c. http://www.fiftyyearfight.org web site, which documents activism related to justice for thalidomiders with material based in part on this research.
- 5.6 EU Parliament press release, 15 Dec 2016 [PDF], corroborating the impact of the ongoing research in bringing thalidomide once again to the attention of European politicians. Also available at: http://www.europarl.europa.eu/news/en/news-room/20161208IPR55202/meps-call-for-better-access-to-compensation-for-thalidomide-victims
- 5.7 UK Parliamentary records, 2nd May 2019, Simon Hoare MP [PDF], evidencing the research having brought the issue to the attention of UK politicians. Also available at: https://hansard.parliament.uk/Commons/2018-05-02/debates/7966615E-C546-44F8-9ACD-AE7D57519DF4/Engagements?highlight=thalidomide#contribution-E1A56271-4260-4979-8FBB-D3709E7DB1AF
- 5.8 Testimonial letter: Secretary to the Board of Trustees of the Thalidomide Society [PDF], corroborating the impact of the book, and specifically Stokes' research contribution, for him as secretary, for members of the Society and for the wider thalidomide community.