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Newsletter No. 22
Cologne, May 2015

Dear Sir or Madam,

Since 1st January 2015, we – the new board of directors – have had the pleasure of continuing the successful work conducted by the foundation in the past.

We – Ms Marlene Rupprecht (Chairwoman) and Ms Margit Hudelmaier – are very happy to have taken on this task and look forward to working with you in a spirit of mutual trust and support.

A new board of trustees has also been in office since 1st January 2015. The current trustees are listed in the attached overview.

We would like to take this opportunity of bringing you up to date with the latest news and most important developments:

Status of the “Grünenthal files”

The law firm instructed to review the files has almost concluded its task. The next step will be to compare the files with the documents held at the offices of the Contergan Foundation. Only by means of comparison can a reliable statement be made as to whether the files are copies of documents already in the possession of the Contergan Foundation, or whether they are hitherto unknown documents.

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The comparison of the documents is to be completed as quickly as possible. We aim to let you know towards the middle of the year whether or not documents concerning you have been found, and will provide you with copies of any such documents.

In addition, the law firm instructed by the Contergan Foundation is in the process of clarifying the facts surrounding the "Grünenthal Files". To this end, comprehensive sets of questions have been addressed to Grünenthal and other persons potentially involved.

Based on the results of the investigation, the necessary measures to be taken will then be decided by the Contergan Foundation.

We will keep you informed of any further developments.

Internet portal

We are pleased to inform you that the contract for the "Internet Portal" project was awarded at the end of 2014. This has enabled us to set about creating the online Information and Advice Network for thalidomide-related issues. The network is scheduled to go live in 2015.

The internet portal is intended to provide a point of contact for people affected by thalidomide who are seeking fast, comprehensive information about statutory benefits and services as well as the public authorities and institutions responsible. Moreover, it should help to improve the exchange of information between people affected by thalidomide, further the transfer of knowledge among experts and make research and other information readily available.

To this end, we ask you to provide our office with the contact details of any institutions, doctors and nursing services specialised in the field of thalidomide.

In order to promote the exchange of experience among those affected, we would urge you to send us information about any aid devices you utilise in your everyday life.

We are keen to find out from you how much such aid devices cost, where they can be obtained, and whether you would be prepared to act as a contact to whom interested parties could address their enquiries directly.

We would like to publish your advice on the internet portal. Alternatively, enquiries from interested parties could be forwarded to you via our office.

Please send any messages relating to this subject to our postal address found at the top of this letter or e-mail us at geschaefsstelle@contergan.bund.de.

The company commissioned with the creation of the internet portal will be assisted by an editorial board. The latter is composed of experts from the fields of journalism, medicine and law, as well as people affected by thalidomide and foundation representatives.

Plain language

Newsletters / Information

Since 2014, plain-language versions of all Contergan Foundation newsletters have been made available to beneficiaries in Germany and published on the Contergan Foundation homepage in addition to the standard documents. This service is in compliance with the requirements of the German Act on Equal Opportunities for Disabled Persons (*Behindertengleichstellungsgesetz – BGG*).

We are pleased to inform you that you now also have the option of receiving information in plain language. Please contact our office if you wish to take advantage of this service.

Sign-language website

Since mid September 2014, the Contergan Foundation has had a new website. The most significant changes include a new navigation system and a “News” section, which is intended to keep you up to date with the latest developments. You will also find a large number of documents on the website (such as claim forms, leaflets and newsletters), which are published in German as well as other languages.

In addition, the website is now available in sign language and plain language.

Special needs

In recent months, the Contergan Foundation has responded to a considerable number of questions relating to “special needs”. The topics most frequently broached by you are outlined below:

Provided you have received a (partial) benefit approval notice from the Contergan Foundation, there are two options available. You can either send the **original** invoice to the Contergan Foundation, which will then transfer the invoice amount to the billing party, or you can pay upfront and send the Contergan Foundation appropriate proof of payment

(receipt or bank statement). The latter will then reimburse you for the invoice amount by means of bank transfer to an account specified by you.

The approved benefit is generally recorded as having been paid in the year in which all the necessary application documents are received by the Contergan Foundation.

Private medical prescriptions and certificates can only be accepted for applications not linked to a benefit claim vis-à-vis a rehabilitation provider.

If private medical prescriptions and certificates were accepted as a general rule, this would lead to the Foundation being unable to assert priority claims. We trust you will understand this policy, even though it may lead to increased bureaucracy in certain circumstances.

This system is designed to benefit you by safeguarding the maximum reimbursement amount at your disposal each year.

The obvious necessity for disability-friendly building conversions is currently not covered by the benefits scheme for persons with special needs. This issue will be examined during the evaluation due to take place later this year.

We would like to point out, however, that the providers of community integration services may be willing to cover the costs. We therefore recommend that you submit an appropriate claim form.

Should you have any questions on this subject, please feel free to contact our office for assistance.

Explanatory leaflet for doctors and dentists

In order to make members of the medical and dental professions aware of the claim process and the range of benefits available to persons with special needs, we have designed two separate leaflets for doctors and dentists. Last year the leaflets were sent to the Federal Association of Statutory Health Insurance Physicians (*Kassenärztliche Bundesvereinigung*) and the Federal Association of Statutory Health Insurance Dentists (*Kassenzahnärztliche Bundesvereinigung*), who in turn forwarded them to their members.

In the course of our daily work, we have come to realise that there is a continued need for information. If you are a beneficiary living in Germany, you will see that we have enclosed both leaflets with this letter for your own information and for passing on to your doctor or

dentist. You are also welcome to download the leaflets in PDF format from our website: <https://www.conterganstiftung.de/service/merkblaetter.html>

Medication Directive (*Heilmittel-Richtlinie*)

We have received reports that you are still experiencing problems with the implementation of section 8 paragraph 5 of the Medication Directive. We therefore wish to point out once again that thalidomide damage is included in the “List of diagnoses requiring long-term medication”. Your doctor is therefore authorised to prescribe drugs for approved long-term treatment purposes in accordance with the Medication Directive without the need for assessments of cost effectiveness.

For beneficiaries living in Germany, we are enclosing the information leaflet together with the attachment headed “List of diagnoses necessitating long-term medication”, which explain the long-term approval procedures required by the National Association of Statutory Health Insurance Funds (*Spitzenverband der Gesetzlichen Krankenkassen*) and the Associations of Statutory Health Insurance Physicians (*Kassenärztliche Vereinigungen*). It is also possible to download both the leaflet and the attachment from the following website: <https://www.g-ba.de/informationen/beschluesse/1595/>

Current situation with respect to the vascular study

In October 2013, the participants of the workshop dedicated to the “examination of possible prenatal damage to the vascular system as a result of taking contergan / thalidomide in pregnancy” decided not to conduct a vascular study for the time being, but instead to offer all persons concerned a voluntary examination of the blood vessels and the back of the eye or bone density. We now wish to take another look at the “vascular study” issue. As an initial step, round-table discussions are scheduled to take place in May with medical experts, representatives of the Federal Ministry of Family Affairs, Senior Citizens, Women and Youth (*Bundesministerium für Familien, Senioren, Frauen und Jugend – BMFSFJ*) and rapporteurs from all political factions. The purpose of the talks is to collate facts on the “vascular status” of thalidomide victims and to discuss the feasibility of a study in detail. The possible benefits and risks will be assessed, and careful consideration given to our future course of action. As members of the board, we consider it imperative to pursue the “vascular study” issue as a matter of priority in the interests of all those affected by thalidomide.

Reporting fatalities and causes of death

We hope you won't mind us now broaching a subject that has long been a sensitive issue for you and your relatives. We can only tackle this problem with your help.

Here is a brief reminder of the situation: According to the scientific study entitled "Regular surveys to be conducted on problems, special needs and care deficiencies with respect to thalidomide victims living in Germany", the cause of death may be linked to the disability. In order to enable conclusions to be drawn about possible health risks facing the thalidomide population as a whole, it is vital that our office be informed of the cause of death. Naturally, this decision lies at the discretion of yourself and your relatives.

We undertake to treat this information in confidence and in compliance with data privacy regulations.

Lobbying by the foundation

Contact with interest groups

On 21st March 2015, a general meeting of the Federal Association of Thalidomide Victims (*Bundesverband Contergangeschädigter e.V.*) took place in Düsseldorf. At that meeting, the board of directors reported on special needs and the figures relating to new claims and appeals, as well as answering questions from victims.

Ms Ruppert also held telephone conversations with representatives from other associations and groups. The topics discussed over the phone were similar to those dealt with at the general meeting of the Federal Association.

Political lobbying before the Family Affairs Committee

On 25th March 2015, the Family Affairs Committee held a session in Berlin, which was attended by the board of directors and the head of office. The chairwoman provided the committee with an account of the work conducted by the foundation and an overview of the current situation with respect to special needs. One of the issues broached was the discrepancy sometimes seen between claims for benefits and benefits actually approved. It was made clear that the statutory regulations cannot be circumvented in the decision-making process, but that they are construed in favour of the persons concerned as far as possible. In addition, it was pointed out that those needs which are not reimbursable under the thalidomide damage guidelines, such as disability-friendly building conversions, will be examined during the evaluation scheduled for this year. Finally, the rapporteurs of the individual political factions answered questions posed by persons affected by thalidomide.

Political lobbying with the Secretary of State Ms Caren Marks

At another meeting also held on 25th March 2015 with the Parliamentary Secretary of State Ms Caren Marks, the former board of the Contergan Foundation was bade farewell and we were welcomed as new board members.

We took advantage of this opportunity to inform Ms Marks about the current topics and concerns of people affected by thalidomide. The Parliamentary Secretary of State showed a great deal of interest.

We wish you all the best for the spring.

Yours faithfully,

The Board of Trustees – 12th Term of Office

Ordinary Members	Deputy Members
<p>Christoph Linzbach</p> <p>Federal Ministry of Family Affairs, Senior Citizens, Women and Youth (<i>Bundesministerium für Familie, Senioren, Frauen und Jugend</i>)</p> <p>Chairman of the Board of Trustees</p>	<p>Dr. Sven-Olaf Obst</p> <p>Federal Ministry of Family Affairs, Senior Citizens, Women and Youth (<i>Bundesministerium für Familie, Senioren, Frauen und Jugend</i>)</p> <p>Deputy Chairman of the Board of Trustees</p>
<p>Dr. Petra Sartor</p> <p>Federal Ministry of Labour and Social Affairs (<i>Bundesministerium für Arbeit und Soziales</i>)</p>	<p>Petra Spätling-Fichtner</p> <p>Federal Ministry of Labour and Social Affairs (<i>Bundesministerium für Arbeit und Soziales</i>)</p>
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<p>Rita Wahlen</p> <p>Federal Ministry of Finance (<i>Bundesministerium der Finanzen</i>)</p>	<p>Elisabeth Wölky</p> <p>Federal Ministry of Finance (<i>Bundesministerium der Finanzen</i>)</p>