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Newsletter No. 25  
Cologne, June 2017

Ladies and Gentlemen,

Much has happened since our last newsletter, which we would like to inform you of. We hope you will enjoy our newsletter and will gladly answer any questions you may have.

## **Fourth Law Amending the Contergan Foundation Act**

### **- Lump sum benefits to cover specific needs -**

As you may know, on 15.12.2016 the German Bundestag enacted the Fourth Law Amending the Contergan Foundation Act (ContStifG), which became effective on 28.02.2017 retroactive to 01.01.2017.

One change, which will be important to you, is consolidating benefits for specific needs into a lump sum. The report from the Federal Government uncovered complex definition issues with respect to granting benefits to cover specific needs and potential for improvement in the process for granting these services.

On one hand, this means services for specific needs will no longer require approval and be subordinate, but instead be paid out to eligible persons as an annual lump sum (from 5,676 euros to 14,700 euro). This lump sum payment will now instead allow you to specify how your funds will be used and what your specific needs are. In March 2017, the office

granted all eligible individuals a single notice granting the annual benefit to cover specific needs.

The annual benefit to cover specific needs for 2017 was paid out on 10.03.2017. Unless the law changes, this benefit will be paid out on 10 January every year thereafter.

**Note:**

In this regard, we would like to refer to § 25 ContStifG, according to which the Federal Government is to first issue a report for the German Bundestag on the effects of the ContStifG, version of the Fourth Law Amending 2017, and further changes to these regulations after two years, where possible supported by documentation on how the funds for specific needs are being used by beneficiaries. The government may therefore be interested at a future point in how you used your lump sum benefits. However, you will not be required to disclose this information.

**- Contergan Foundation for Disabled People consultation -**

In addition to granting a lump sum benefit to cover specific needs, when the Fourth Law Amending the Contergan Foundation Act became effective, lawmakers also included a new consultation offer:

We are happy to announce that **effective immediately** the Contergan Foundation will also be your contact to serve as a “**guide**”.

As a first step, this means that staff working in specific needs will be here to assist you with a variety of topics, e.g. questions related to various payers within the German social system, based on their experience from recent years.

Please feel free to phone or e-mail us at  
(+49(0)221-3673-3673 or [geschaefsstelle@contergan.bund.de](mailto:geschaefsstelle@contergan.bund.de))!

The second step will be expanding the consulting services, as the Contergan Foundation is also still working on processing specific needs until the third quarter of 2017.

## **Vascular study**

In newsletter no. 24 from December 2016, we informed you of the meetings with experts from angiology, cardiology, neurology, anesthesia, cardiac and thoracic surgery, radiology, epidemiology as well as data privacy and freedom of information held in June and October 2016. We furthermore informed you of the pilot survey based on the 109 vascular surveys, which had been submitted by some affected persons at that time: Due to the heterogeneity of the data, it is not possible to establish a causal connection between the prenatal intake of Contergan by the mother and the long-term vascular damages.

Expert Dr. Peter Klein-Weigel, MD, presented the Foundation Board with detailed results of the survey at the 104th meeting on 05.04.2017 in Berlin. A potential next step may be to conduct a vascular study where standardized, and thus comparable, studies can be conducted at select research centers in compliance with the data protection law.

The Foundation Board made it clear that conducting this type of study would not be covered by the original resolution of the foundation board and would therefore require a new resolution. Estimating the cost/benefit of this type of study would require a model which shows the individual study modules including objectives, time frame and the anticipated costs.

The Foundation Board will use this information to determine whether to conduct a vascular study by written resolution. If the Foundation Board decides to conduct a study, it would then be required under public procurement provisions to call for tenders.

For more information on this topic, please see "Vascular study status report" under "News" on the Contergan information portal (CIP for short). We will keep you informed of the latest news on this topic.

### **Note:**

In this regard, we would also like to point out that due to the lump sum payment to cover specific needs enacted by the Fourth Law Amending the Contergan Foundation Act, the costs of a vascular study are no longer covered.

### **Helping other affected persons through exchange of experiences**

In our last newsletter we asked: Do you have an aid with which you are particularly satisfied? Or were you ever in a rehabilitation facility where you felt particularly comfortable? Then share your experiences with other affected persons.

Please continue to submit any information about rehabilitation or other treatment facilities and aids you use on a daily basis to the address in the letterhead or e-mail [geschaefsstelle@contergan.bund.de](mailto:geschaefsstelle@contergan.bund.de)!). We look forward to your suggestions and tips, which we would like to publish on our portal with your consent.

We would like to thank anybody who has already submitted their experiences.

Please also let us know if you are willing to serve as a contact for others and share your experience. Simply phone or e-mail the office at +49(0)221-3673-3673 or [geschaefsstelle@contergan.bund.de](mailto:geschaefsstelle@contergan.bund.de)!).

### **Contergan information portal: RSS feed will soon replace mailing lists**

The CIP is quite popular: Since its launch, the portal has had about 57,376 hits. During the 1st quarter of 2017 alone, the Contergan information portal had about 19,627 hits.

This is due not least to the CIP editorial board's commitment to provide you with informative and well-rounded content on "Life with Contergan". We would like to further expand the work between the editorial board and the Contergan Foundation board and office to consistently make contents on the Contergan information portal easier to navigate, up to date, and aimed better at those affected.

The editorial board took up your idea to add a so-called RSS Feed: Since April 2017 the menu bar on the home page [www.contergan-infoportal.de](http://www.contergan-infoportal.de) now has an icon which allows you to add the RSS Feed. "RSS" stands for "Really Simple Syndication". This file format provides the recipient with quick information on news which has been add-

ed to the website. For details on how to subscribe to the RSS Feed, please visit [www.contergan-infoportal.de](http://www.contergan-infoportal.de).

In the long term, the RSS Feed is intended to replace the mailing list from the office. We will notify you before this service has been finalized. Until then, you will continue to also receive all online news by e-mail.

If you have any questions about the RSS Feed, please e-mail us at [info@contergan-infoportal.de](mailto:info@contergan-infoportal.de). The same applies to any other matters. We look forward to your diverse and constructive feedback.

### **Grünenthal files: Final investigative report published**

Processing the newly found Grünenthal files went well. In our newsletter no. 24 from December 2016, we reported the Contergan Foundation sent out about 1,700 datasets (as of calendar week 43).

We are happy to inform you that, in early March 2017, staff completed processing documents from those affected with names starting with "Z". An addition, 41 files were still being reviewed by the Medical Commission, most of which were also completed in early March 2017.

Since mid-March 2017, staff have been processing the approx. 550 old denials, some of which required extensive domestic and international address and name searches. The status for May 2017 (as of calendar week 20) is now at 193 cases processed.

This means that to date, 2,717 (as of calendar week 20) of the approx. 3,200 individuals affected have been notified of documents discovered and of the contents. This means that almost all affected Germans and old denials have been completed.

For over two years, a law firm hired by the Contergan Foundation in this case worked on establishing the backgrounds of these files, reviewing the process in terms of data protection law, establishing the necessary consequences, and advising and representing the Contergan Foundation in implementing the measures. It has now compiled an extensive closing report on its findings, an update to the 14 April 2015 progress report you are familiar with.

The report is being sent to all those affected who either already have or will be receiving Grünenthal documents. You may further access the report in the CIP using the following link:

[http://www.contergan-infoportal.de/dokumentation/aktuelles\\_archiv/aktuelles\\_aus\\_maerz\\_2017\\_aktenfund\\_abschlussbericht\\_sachverhaltsermittlung/](http://www.contergan-infoportal.de/dokumentation/aktuelles_archiv/aktuelles_aus_maerz_2017_aktenfund_abschlussbericht_sachverhaltsermittlung/)

The facts discovered by the law firm will be used to take further action. One important initial consequence is the drafting of the “guidelines for handling data and files at the Contergan Foundation”. Relevant drafts for the various bodies and committees of the Foundation are available, and will be discussed and agreed upon by the people involved and the law firm appointed to address queries regarding data privacy.

The foundation further felt obligated to lodge a complaint against one party with the Aachen public prosecutor’s office. It had found indications that the party’s behavior was a criminal and administrative offence. However, in a letter dated 01 March 2017, the public prosecutor's office notified the foundation that the actions had become time-barred and had therefore stopped the inquiry for this absolute bar to proceedings.

**Note:**

We would again like to point out that if you received Grünenthal documents from the office, you may, as an “injured party”, lodge a complaint against Grünenthal GmbH. The deadline for lodging the complaint is 3 months from the time you became aware of the offender or offence, i.e. from the time you received the documents.

**Return of benefits in the event of death**

The office receives a lot of questions as to whether the Contergan Foundation may demand benefits be returned in the event of a death. We would like to take this opportunity to educate you about this topic and the provisions.

**Annuity**

Under § 9 Paragraph 2, the Contergan provisions state the Contergan pension will stop at the end of the month the beneficiary passes away. Any benefits paid after the month the beneficiary passes away must therefore be demanded returned under § 13 Paragraph 8 Contergan Foundation Act.

**Annual special payments, lump sum payments to cover specific needs**

Under § 11 of the Contergan provisions, the annual special payment is an annual benefit paid once a year. It is connected to receiving the Contergan pension. Under § 11 Paragraph 1 of the Contergan damage guidelines, the annual special benefit is to be transferred to beneficiaries on March 1st of each year, i.e. due at this said time. If the benefi-

ciary is alive at the time this benefit is paid, the benefit cannot be returned, including prorated amounts, if the beneficiary passes away at a later time.

Example:

The annual special benefit is transferred on March 1st and deposited in the beneficiary's account on March 3rd. The beneficiary passes away on March 15th. In this case, the payment cannot be demanded returned, as the beneficiary was still alive at the time the benefit was paid out and was therefore entitled to this benefit.

The lump sum payment to cover specific needs works the same as the annual special payment. It cannot be demanded to be returned if the benefit was already paid while the beneficiary was alive.

### Capitalization

If there are active capitalizations at the time the beneficiary passes, the foundation is not entitled to demand benefits for the remainder of the settlement period be returned (§ 10 Paragraph 2 c charter of the Contergan Foundation for Disabled People).

For the sake of completeness, we would also like to point out the provisions under § 13 Paragraph 5 Sentence 2 of the Contergan Foundation Act in this context. This applies if benefits were already due but still pending at the time the beneficiary passed. In these cases, you are only entitled to the benefit if the beneficiary inherits from their spouse, domestic partner, children or parents.

If you have any questions about this matter, please contact one of our staff members (+49(0)221-3673-3673 or [geschaefsstelle@contergan.bund.de](mailto:geschaefsstelle@contergan.bund.de)!).

### **Lobbying: Contergan Foundation - An important interlocutor**

Lobbying is coming to fruition. Also in the previous reporting period, the Foundation regularly and intensively exchanged information with decision makers in parliament, ministers and federal data protection agencies on all matters relevant to thalidomide-affected persons. Specifically, on 28.11.2016 the board attended a closed session to hear the draft of the "Fourth Law Amending the Contergan Foundation Act" at the 76th meeting of the Committee on Family Affairs, Senior Citizens, Women and Youth.

## Higher pensions as of 1 July 2017

As of 1 July 2017, pensions will increase by 1.9 %. The pension rates are:

<b>Points</b>	<b>monthly Contergan pension</b>
up to 9.99	only lump-sum settlement §13 paragraph 2 page 3 of the Contergan Foundation Act
10 - 14.99	675 euro
15 – 19.99	1,034 euro
20 – 24.99	1,410 euro
25 – 29.99	1,803 euro
30 – 34.99	2,204 euro
35 – 39.99	2,768 euro
40 – 44.99	3,391 euro
45 – 49.99	4,066 euro
50 – 54.99	4,320 euro
55 – 59.99	4,573 euro
60 – 64.99	4,827 euro
65 – 69.99	5,208 euro
70 – 74.99	5,590 euro
75 – 79.99	5,970 euro
80 – 84.99	6,351 euro
85 – 89.99	6,733 euro
90 – 94.99	7,178 euro
95 – 100	7,622 euro

The provisions of the Contergan Foundation Act in § 13 paragraph 2 stipulate that the Contergan pension is increased annually based on changes to the statutory pension.

Best wishes from Cologne

  
Marlene Rupprecht

  
Margit Hudelmaier

  
Kristina Kruse