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Newsletter No. 24
Cologne, December 2016

Dear Sir/Madam,

Once again there have been many new developments since our last newsletter. We would like to tell you about these developments. We hope you enjoy reading the newsletter.

CIP now the exclusive “showcase” of the Contergan Foundation

Since 27 November 2015, the Contergan Info-portal (in short: CIP)] has been operated and managed alongside the Foundation’s homepage. Since the 1 July 2016 it has been the exclusive “showcase” of the Contergan Foundation, the usual homepage at www.conterganstiftung.de has been shut down. Most importantly: Should you enter the usual address into the browser - that won’t be a problem, you will be redirected to the new address.

This change was announced in Newsletter No. 23, and has now been implemented because the analyses showed that the CIP is being very well received. Since its launch the portal has been recording around 2,470 hits every month.

One of the reasons: In addition to the usual content of the previous Foundation website, CIP includes a variety of information, addresses, links and tips on all questions related to

Address for visitors:
For general enquiries, please call the service hotline for the
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E-Mail geschaeftsstelle@contergan.bund.de

Telephone: + 49 (0)221 3673-3673
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Website: www.conterganstiftung.de

Contergan Foundation for Disabled People
Helpline no.: 0800 570 0570
Office hours: Monday to Friday, 7:30 am - 4:00 pm
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health, participation and finance. Furthermore, an experts forum as well as a forum of affected persons facilitate a mutual exchange of knowledge and experiences. More help for the affected persons--this is the central idea behind CIP.

Of course, the portal visitor needs to first get acquainted with the changed structure and user logic. Therefore, in the coming days we would like to introduce to you the structure and the schedule for upgrading the portal. In case you are unable to find particular content, or if you have any questions or suggestions regarding improvement, please send us an e-mail at info@contergan-infoportal.de. Also, if there are topics that “prey on your mind” which you would really like to know about the CIP, then we would be happy to receive your comprehensive and constructive feedback.

Specific needs: Financial risk in the case of advance payment

Here we would like to report on an actual case: An affected person’s plan had a provision linking the stay abroad with out-patient rehabilitation facilities. The travel agency had organised the entire trip and presented the total invoice way ahead of the start of the journey--including the rehabilitation facility costs. The point we are trying to make here is: In such a case, you directly expose yourself to a financial risk. When you plan without having a notification of approval in hand, the Foundation cannot assume any liability in case the approval is not granted. On the other hand, should you delay the payment until you receive the approval, the Foundation cannot compensate for any overdue fines that may be incurred.

Furthermore, the Foundation can unfortunately also not provide any kind of advance payments, as the Foundation Board is legally required to use the Foundation funds economically and sparingly. This legal requirement does not go hand in hand with advance payments and the insolvency risk associated with it. However, you may rest assured that the Contergan Foundation endeavours to process payments as fast as possible after the service has been provided and the documents substantiating the payment have been duly received.

Evaluation: Studies now available on CIP

The evaluation report required by the Contergan Foundation Act every two years is now available. The aim of this year's evaluation in particular is to determine the effects of service improvements due to the Third Amendment to the Contergan Foundation Act as well as to examine the procedure for granting benefits to cover specific needs.

Two expert reports were assigned:

- The "Expert report on benefits to beneficiaries in accordance with the Contergan Foundation Act" [German original: *Expertise über die Leistungen an Leistungsberechtigte nach dem Conterganstiftungsgesetz*] was prepared--as expressly requested by the representatives of the affected persons in the Board of Trustees --by Prof. Dr. Dr. h. c. Andreas Kruse of the University of Heidelberg.

- Ms. Gila Schindler, certified attorney specialising in social law, was responsible for the "Expert report on the procedure for granting benefits to beneficiaries to cover specific needs in accordance with the Contergan Foundation Act" [German original: *Expertise über das Verfahren der Gewährung von Leistungen zur Deckung spezifischer Bedarfe an Leistungsberechtigte nach dem Conterganstiftungsgesetz*].

The results of both investigations were submitted to the Ministry of Family Affairs, Senior Citizens, Women and Youth [*Ministerium für Familie, Senioren, Frauen und Jugend (BMFSFJ)*]. Based on these expert opinions submitted the *BMFSFJ* prepared a report, which was presented to the German Bundestag on 08.06.2016. Both expert reports have been uploaded onto the CIP and can be accessed via the following link:

http://www.contergan-infoportal.de/finanzen_recht/rechtsgrundlagen/evaluati-on_des_conterganstiftungsgesetzes_25_contstifg/

The respective summaries of the expert reports are currently being rendered into plain language. Needless to say, we will inform you as to when these will be available online for download.

Specific needs: Future developments and benefit plans

The responsible committees are presently discussing an amendment to the regulations for specific needs. At present it is uncertain as to whether this would result in a new regulation, and if yes, what would be its configuration. You can, therefore, claim your benefits as before and should submit your application--if you have all your documents together--**by 31.12.2016 at the latest**. In this way, you can ensure that the current legal provisions are still applicable to these applications, provided you have claimed the benefits in year 2016 or initiated the measures in 2016. In the event of a change in the regulations, the office staff of the Contergan Foundation will be glad to assist you in queries regarding your specific case.

Vascular study: Heterogeneous data

We had requested that you send in the results of your vascular examination to the Contergan Foundation. The aim is to conduct a study in order to be able to assess individual health risks and ensure optimum treatment in the case of emergency. As recorded on October 2016, 124 affected persons have sent their examination reports to the Foundation.

We would like to thank you for your active interest as well as your trust in us.

Based on this data, expert meetings were held on 06.06.2016 and 11.10.2016 in Cologne at the office premises of the Contergan Foundation; experts from the specialist fields angiology, cardiology, neurology, anaesthesia, cardiac and thoracic surgery, radiology, epidemiology as well as data privacy and freedom of information attended these meetings. The participants also included the Board of the Contergan Foundation as well as the office manager and two office employees.

The most important outcomes:

The data material is very heterogeneous and includes various extensive examinations of different vascular regions using varied examination methods.

Some of the examinations are also not complete.

And last but not least, the option of examination was used to a large extent by people with lower degree of disability and not by severely or seriously affected persons.

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 damag-

es. Abnormal courses of the vessels need not necessarily point to thalidomide; instead, they also occur in the non-affected population.

The submitted data was first analysed in a pilot investigation to see whether one could detect any trends and there could be any indications of possibly affected vascular regions. A possible next step could then be to conduct a study, in which the anonymised examination results could be evaluated with the help of a standardised examination.

Observing data privacy during the investigation and a possible follow-up study were matters of special concern for all participants.

For this reason, the evaluations were performed by keeping the names strictly confidential, i.e. with no possibility of direct identification of a person. The data processed in this way was entered in a database for statistical evaluation. The results of the evaluation were presented to the Committee and the Board, and discussed. Dr. Klein-Weigel will be presenting the results of the evaluation as well as the experts' suggestions regarding the next course of action in the matter of "vascular study" to the Board of Trustees in its next meeting.

Grünenthal files: Data transfer in full swing

We are making progress in the Grünenthal files matter. In Newsletter No. 23, dated November 2015, we had reported that the process of sending the compiled personal data to the affected persons had been initiated. We are pleased to inform you today that we have made considerable progress in the matter: Meanwhile, the Contergan Foundation has sent around 1,790 records (status in 43rd CW). This is more than half of the total records. The Contergan Foundation as well as the appointed law firm will continue to provide clarifications on all open questions regarding the "Grünenthal files". Result: Grünenthal GmbH has confirmed that it has in the meantime destroyed and deleted all its digital and analogue records.

Regarding further action the Foundation has presently come to an arrangement with the Federal Commissioner for Data Protection and Freedom of Information.

The next steps will be taken based on this arrangement. An important consequence is the drafting of the "guidelines for handling data and files at the Contergan Foundation". Meanwhile, 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.

Files at the paediatric orthopaedics department, Universitätsklinikum Münster

As some of you may have heard already, patient files of affected persons, who were treated at the Universitätsklinikum Münster [university clinic in Münster, Germany] during childhood, are kept at the paediatric orthopaedics department of the Universitätsklinikum Münster. We would like to clarify that these are files with patient data and do not include files of a public authority or agency, or even files of the Contergan Foundation for Disabled People. Only the respective affected persons are entitled to retrieve these files.

Helping all affected persons through exchange of experiences

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. For it holds good even in this case: a joy shared is a joy doubled.

Please send us the information regarding rehabilitation or other treatment facilities as well as aids that you use in your daily routine. The important questions are: How expensive are these aids, from where can they be acquired, and whether you as the user are also available as a contact person for any enquiries from the affected persons. We would be glad to publish your recommendations on the internet portal. Alternatively, enquiries of interested people could also be forwarded to you as the contact person via the office.

You may send any information relating to this subject to our postal address mentioned in the letterhead or e-mail us at geschaefsstelle@contergan.bund.de. We look forward to your suggestions and tips!

Reporting fatalities and causes of death

The demise of a person is always sad and should be handled with all due piety. If, however, we do contact you regarding this topic, it is because the cause of death of an affected person may provide indications of possible health risks--and thus life-sustaining measures--for all affected persons.

This correlation is at least established in the study “Regular surveys on problems, special needs and care deficiencies of thalidomide victims” [German original: *Wiederholt durchzuführende Befragungen zu Problemen, speziellen Bedarfen und Versorgungsdefiziten von contergangeschädigten Menschen*], spearheaded by Prof. Dr. Dr. Andreas Kruse.

To be able to come closer to this theory using scientific methods, it is important to have as much data as possible. The larger the data material, the better. Therefore, we would request the relatives and loved ones of the deceased affected persons to inform the Contergan Foundation office about the cause of death. We assure you that all data will be treated confidentially and in accordance with the data privacy regulations.

Survey: Who would like to receive the newsletter in plain language in the future?

To comply with the requirements of the Federal Act on Equality for People with Disabilities [*Behindertengleichstellungsgesetz (BGG)*], the Contergan Foundation for Disabled People also sends newsletters in plain language. The *BGG* applies primarily to public agencies and authorities, and is intended to eliminate and/or prevent discrimination of people with disabilities. It also aims to ensure equal participation of people with disabilities in social life and enable them to have a self-determined lifestyle. For example, official notices on accessibility should also use plain language.

In this sense, plain language becomes an officially recognised medium of making communication and information accessible to all. Plain language contributes towards the better understanding of texts particularly by, but not limited to, people with hearing disabilities, who are also included in the list of addressees of the Contergan Foundation.

For this reason, since 2014 the Foundation sends its newsletters to all affected persons twice: once in Standard German, once in plain language.

Some affected persons have expressed their disapproval at this double delivery. We regret this. We would like to send our language versions to the appropriate target audience. Therefore, we request those who **do not** wish to receive the plain language version to confirm this in the enclosed form. It is undoubtedly better that everyone receives too much information than having one affected person not receive a piece of important information.

We hope that this will put the discontent of those few individuals to rest. Thank you for understanding!

New telephone service: What do you think?

As already informed in April on the CIP, the Contergan Foundation office has a new telephone system, which considerably improves the service for the affected persons. Instead of the usual dial tone, you now hear a service message that prompts you to specify “your” service area using the numeric keys 1 or 2. The keys are assigned as follows:

Numeric key 1:

For everything related to the areas “specific needs” and “vascular system”.

Numeric key 2:

For all other information requirements.

Initial experiences show that this method enables quicker and more efficient processing and reduces the effort needed by those calling.

Despite these changes, you will continue to have the “close connection” with your desired contact person. You can simply dial his/her personal extension number to bypass the selection menu. In addition, you also have the option to state your request or concern outside of office hours by leaving a message on the answering machine along with your name and telephone number.

The office has installed this system to meet the often expressed need of better reachability. We hope that we have been able to achieve this. Therefore, your opinion is important to us: What do you find good, what not so good? Please give us a call or send your feedback via e-mail to geschaefsstelle@contergan.bund.de.

Lobbying: Contergan Foundation - An important interlocutor

In the previous reporting period too, the Foundation regularly exchanged information with decision makers in parliament, ministers and federal data protection agencies on all matters relevant to thalidomide-affected persons. On 19.09.2016 in particular, the Board participated in an unofficial expert discussion of the Committee of Family Affairs, Senior Citizens, Women and Youth on the topic “First report of the Federal Government on the implications of the Contergan Foundation Act as well as on any necessary enhancements of these regulations” [German original: *Erster Bericht der Bundesregierung über die Auswir-*

kungen des Conterganstiftungsgesetzes sowie über die gegebenenfalls notwendige Weiterentwicklung dieser Vorschriften]

Life certificate 2017

In January 2017 we will once again require your life certificate. We had sent you a separate letter in October 2016 in this regard and had requested you to send the filled out certificate by 31.01.2017.

The form is, of course, also available to you online. You may download it using the following link:

http://www.contergan-infoportal.de/service/antragshilfen/antraege_und_formulare/?tag=18

Capitalisation calculator

A new feature on the Contergan information portal is the pension capitalisation calculator. With its help you can calculate the paid amount or the monthly pension amount on your own. Please note, however, that all information provided there is subject to correction and is supplied without liability. The capitalisation calculator is solely for the purpose of orientating your individual plan. The final calculation by the Contergan Foundation office, which is legally valid and is reflected in the official communication regarding capitalisation, shall be decisive.

The calculator can be accessed online via the following link:

http://www.contergan-infoportal.de/finan-zen_recht/leistungen_stiftung/rentenkapitalisierung/rentenkapitalisierungs_rechner/

Higher pensions since 1 July 2016

The following pension rates are effective 1 July 2016:

| Points | monthly Contergan pension |
|------------|---|
| up to 9.99 | only lump-sum settlement §13 paragraph 2 page 3 of the <i>ContStifG</i> |
| 10-14.99 | 662 EUR |
| 15-19.99 | 1,015 EUR |
| 20-24.99 | 1,384 EUR |
| 25-29.99 | 1,769 EUR |
| 30-34.99 | 2,163 EUR |
| 35-39.99 | 2,716 EUR |
| 40-44.99 | 3,328 EUR |
| 45-49.99 | 3,990 EUR |
| 50-54.99 | 4,239 EUR |
| 55-59.99 | 4,488 EUR |
| 60-64.99 | 4,737 EUR |
| 65-69.99 | 5,111 EUR |
| 70-74.99 | 5,486 EUR |
| 75-79.99 | 5,859 EUR |
| 80-84.99 | 6,233 EUR |
| 85-89.99 | 6,607 EUR |
| 90-94.99 | 7,044 EUR |
| 95-100 | 7,480 EUR |

The up-to-date table can be accessed online via the following link:

[www.contergan-
infopor-
tal.de/finanzen_recht/leistungen_stiftung/die_conterganrente/tabelle_conterganrente/](http://www.contergan-infoportal.de/finanzen_recht/leistungen_stiftung/die_conterganrente/tabelle_conterganrente/)

New discount rate

Since 01.10.2016 the discount rate is: 0.28%.

Closing date

The Federal Cash Office has its closing date on 09.12.2016. This means that from this date onwards the Contergan Foundation will not be able to initiate any more transfers. Therefore, please note that although we can process the payment instructions received after 07.12.2016, the payments, however, will be made only from 02.01.2017.

The Board of the Contergan Foundation for Disabled People and the office team warmly wishes you and your family a pleasant Advent season, a merry Christmas, and a healthy and successful year 2017.


Marlene Rupprecht


Margit Hudelmaier


Kristina Kruse

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Newsletter in plain language

Last name, first name:

STC II:

I **no longer** want to receive the newsletter of the Contergan Foundation for Disabled People in plain language.

.....
Date

.....
Signature

Please find below the various options for sending the form. **We request you to please use one of them:**

- FAX
- or
- Post
- or
- E-Mail as scanned PDF document.