Hello everyone!

You’re currently reading our April newsletter! This month, we decided to focus on two major topics: On the one hand, we inform you about the differences between collecting and hoarding as outlined in a recent scientific article; and give you an example of a very creative collector who turned her penguin collection into a penguin museum. On the other hand, we decided to focus on the difficulties relatives of hoarders are facing. We are extremely thankful to Donna Austin, Elizabeth Nelson and Rose Edmunds from “Children of Hoarders Inc.” who very kindly agreed to write something about their experiences as a child of a hoarding parent for our April newsletter. “Children of Hoarders Inc.” is a non-profit organization that aims to improve the lives of children of hoarders. If you’d like to find out more about them, just visit their website at www.childrenofhoarders.com.

Our second hoarding support group meeting took place on 5th of April and we really enjoyed the open and vivid discussions in the group. Moreover, we were very impressed by the huge efforts and motivation of all group members and the great progress some members already managed to make. We’re expecting some new members to attend our next meeting and if YOU think you might have a hoarding problem, don’t hesitate and just come along! Our next meeting takes place on Thursday 3rd of May.

Last but not least, we would like to invite everyone happy to share some hoarding-related experiences, knowledge, etc. to get in touch with us and write a few lines for our May newsletter. We’re always happy to hear from you!

Very best wishes, the CHAnGE- Team
CHANGE ACTIVITIES

• **Support group**: On Thursday 5\textsuperscript{th} of April, our second monthly support group meeting for people with hoarding problems took place at the Eric Liddell Centre. Our group was a little bit smaller than in March, potentially because some group members were away for Easter. We had a very nice atmosphere during the meeting and talked about “reasons to change” and “reasons not to change”. Moreover, we had some lively discussions about hoarding and strategies to declutter. We were very impressed that all group members made great efforts to work on their “5 minutes a day” decluttering task and that most of them managed to make great progress. Congratulations! We would especially like to invite everyone suffering from hoarding problems to come (back) to our meetings, particularly if the decluttering homework turned out to be a very difficult one for you. Please don’t give up and give it another chance – the progress by some of the other group members might inspire you tremendously and we had such a great atmosphere of motivation last time! The homework for this month included to keep on doing the “5 minutes a day” decluttering task and to bring an item (or a photograph of it) that you commonly hoard/collect with you to the next group meeting. As promised, we won’t ask anyone to throw it away!

• **Website and Forum**: We updated our website recently and included an *online forum*. We thought that all group members with internet access will love the idea of sharing hoarding problems, thoughts, good and bad news with the other group members not just monthly during the support group meetings but whenever they wish to instead. The forum has a password protected area for CHAnGE support group participants and also open areas for sufferers and relatives of hoarders. At the moment, there is not much activity going on at the forum but we hope that this situation might change once more people have heard about it. Fingers crossed!

• **Hoarding in the “news”**: In our March newsletter, we wrote about the online blog of “Hoarder’s son”. We were happily surprised when we saw that Joe - the blog writer himself - read our newsletter and wrote something about CHAnGE on his blog in return. Thanks for the kind words, “Hoarder’s son” and keep on writing your creative blog! You can find his blog at [http://hoardersson.blogspot.co.uk](http://hoardersson.blogspot.co.uk).
• **Other activities:** We’ve been in touch via phone and email with some more people with hoarding problems living in Scotland. Moreover, we visited a very friendly woman at her home to give her some information about hoarding and sources of help. We realize that many sufferers are a little bit anxious to attend our meetings for the first time but we can only assure you that we’re all very friendly people and that there’s absolutely nothing to worry about. Everyone suffering from hoarding problems is warmly invited to attend our group! There’s one story we hear again and again from people who contact us for the first time seeking help: They have been to their GP, bravely trying to find help for their hoarding problem and the GP says that he doesn’t know anything about hoarding. We strongly hope that this situation will change in the future and we will try hard to raise the awareness for hoarding in the UK.

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**LATEST RESEARCH FINDINGS**

• **Hoarding versus collecting: Where does pathology diverge from play?** – published by Ashley E. Nordsletten and David Mataix-Cols in *Clinical Pathology Review 32* (3), pp. 165–176 in March 2012:

What is the difference between hoarding and collecting? And how well can the proposed criteria for hoarding disorder differentiate someone who suffers from hoarding problems from someone who is a “collector”? These are the questions that Ashley E. Nordsletten and David Mataix-Cols try to answer in their newly published scientific paper.

The authors reviewed the scientific literature of hoarding and collecting. While only about 2.5% of the population appear to suffer from severe hoarding problems, collecting behaviour is much more common: up to a third of adults engage in collecting at any given time. When comparing hoarding and collecting with each other, it becomes obvious that both share a majority of features with other.

Both people with hoarding problems and collectors commonly have difficulties discarding their possessions regardless of their actual value because they feel strong urges to save items and/or experience discarding as very distressing. Moreover, both conditions usually result in the accumulation of a large number of possessions. If someone has a severe hoarding problem, these large amounts of possessions clutter active living areas of the home to the extent that their
intended use is no longer possible (e.g., sitting on a sofa, cooking in the kitchen). However, this appears mainly NOT to be the case when it comes to collecting. People with large collections usually emphasize on order and organization which in turn limits the amount of clutter in active living areas. Another difference between hoarders and collectors is that hoarding causes distress or impairment in daily life but collecting is usually experienced as a pleasurable hobby that does not cause regret or impairment in daily functioning.

To summarise, collecting and hoarding behaviour share several characteristics with each other. However, the two can usually be well differentiated when the amount of clutter in the active living area at home and the potential distress and impairment caused by the accumulation of the possessions is considered. People who hold collections generally do NOT have their active living areas cluttered to such an extent that their intended use is no longer possible. Moreover, they do NOT regret their collecting behaviour or feel impaired by it. It should be noted, however, that some cases of extreme collecting exist where collecting meets criteria for hoarding.

COLLECTING IN ITS MOST CREATIVE FORM

- The Penguin Museum in Cuxhaven (Germany) houses the world’s largest collection of penguin-related items. A Guinness World Record:

As you might have read in the section “latest research findings” of this newsletter, collecting behaviour is usually very well distinguishable from hoarding. To give you a better idea of someone who certainly can be described as a “collector”, we like to inform you about Birgit Berends and her penguin museum in Cuxhaven (Germany). Inspired by a film about penguins, Mrs. Berends started to collect penguin-related items at the age of 18. When her home became full of penguins, she decided to turn her collection into a penguin museum which can be visited by tourists. So far, she collected more than 11,000 penguin-related items – from penguin towels to penguin cups to penguin toys to penguin postcards. If you’d like to find out more about this extraordinary collection, just visit her website at www.penguin-museum-cuxhaven.de.tl.
HOARDING FROM A RELATIVE’S PERSPECTIVE

Compulsive hoarding is a highly debilitating condition. Severe hoarding results in cluttered living spaces that cause distress or impairment in daily functioning. Moreover, the piles of accumulated items are associated with substantial health and safety risks as they can cause fire, falling or illness due to poor sanitation. Finally, hoarding has been associated with marked occupational impairment, poor physical health, social impairment, and a low quality of life. But what about the relatives? And in particular, what about the children of hoarders? How do they cope with the hoarding situation at their home?

We are extremely thankful to the “children of hoarders” Donna Austin, Elizabeth Nelson and Rose Edmunds for sharing their experiences with us and for giving us a better insight into the difficulties relatives are facing when growing up with a parent who hoards. Donna Austin is the founder of “Children of Hoarders Inc.”, a very impressive and inspiring non-profit organization that aims to improve the lives of children of hoarders. You can find their very informative website at www.childrenofhoarders.com. Elizabeth Nelson is also involved in “Children of Hoarders” and talked about hoarding from a relatives perspective in the “Anderson Cooper Show” recently. Rose Edmunds coordinates a meet-up for “Children of Hoarders” in the UK and wrote the novel “Never Say Never”.

Thank you all soooo much for your contributions to this newsletter!

- The foundation of “Children of Hoarders Inc.” and personal experiences with a hoarding mum - by Donna Austin

How Did ‘Children of Hoarders’ Start?

In February 2006, there were a few online support groups for friends and family members of hoarders, but none that focused exclusively on the unique challenges facing those with a parent who hoards. I was seeking more of a connection with those who grew up in hoarder’s home and didn’t have a choice in the matter, who also had the legacy of possessions hanging over their heads. A connection with those who also wanted desperately to help their hoarding parent, but just didn’t know HOW. I had lots of feelings to process and craved a safe place to do so, free from judgement, among those who really understood because they had and were, living it too.
Also at that time there were a handful of websites about compulsive hoarding, but none directly focusing on the issues facing children of hoarders (COH) growing up in a hoarder’s home, their challenges in adulthood resulting from that status, or where to find resources by area, to help our parents. In addition, there was nowhere to publicly read first-hand experiences from other children of hoarders. We needed to know we weren’t alone. Contrary to some opinions out there, the COH site was not created to vilify our hoarding parents, our children’s grandparents. It was to offer us some desperately needed validation, understanding, and support, where our voices mattered and were heard.

So the children of hoarders online support group and website with the headline "Finally Talking About The Family Secret" were created. Visitors were asked to submit their stories about growing up in a hoarder’s home to the website anonymously, starting with 'Tracy's Story,' submitted by a daughter who recently lost her beloved mother. The site received so many story submissions, 3 years later we had to stop receiving them.

Moving Forward

Today, it is a much different story with a plethora of websites, television shows, support groups, blogs and community forums on the topic of hoarding, their families, and resources. Thankfully, many more chances for hoarding families to find community and support- each one offering another benchmark in reducing the stigma and reinforcing the message for those who hoard and their family members, of "You Are Not Alone."

In our peer to peer online support group for the adult COH, we stress that we don't have any magic answers to 'fix our parents,' but can share our insights and experiences in the hopes of supporting each other through whatever the situation at hand may be.

On any given week, our experiences can range anywhere from a member needing to perform a partial clean-out so a hospital bed can be brought in for their ailing parent... to going through possessions when a hoarding parent has passed away and feels guilty about discarding their things ... to just plain rants... to cheering about progress in COH & hoarding awareness or when a parent makes progress... to joking about things only other COH can find the humour in...to talking about our own hoarding tendencies...to how to clean...to discussing feelings of not feeling 'worthy'...to things we love about our parents...to discussing "Doorbell Dread," a term one of our group members created about a common adult trait in having discomfort letting visitors in our
homes as adults. Even when our homes are spotless. We are strictly the children of hoarders, supporting other children of hoarders. And we are not alone.

Personally

On a personal note, my relationship with my hoarding parent has improved 1000% since finding fellowship and validation with/through other children of hoarders over the past 6 years. My mother and I used to argue all the time, we’d even have periods of estrangement due to our arguments about her hoarding, associated traits, and my reactions to it/them. I was a threat to her by constantly challenging and threatening to take away the very things that made her feel safe and comforted. When all I wanted for her, was to BE safe and comfortable.

While I’m not perfect, I try my very best to no longer engage the hoarding disorder in arguments. It’s a powerful force, this hoarding disorder passed down to my mother through generations of afflicted family members that she does not want treatment for. It will always win- I can’t reason with it, so I no longer try. (Well, remember the "I’m not perfect" part, but I try hard!) This has opened coveted ‘space’ for other things between she and I. As long as she is safe and things are functional in her home, that is a good day for this daughter now.

The most valuable lesson I have learned, thanks to the shared experiences from other COH, is that it is not my fault, and I can’t change my mother, I can only change my reactions, myself. A lesson I hope through our advocacy efforts, can be learned much sooner than I did, for the COH growing up behind me.

Thank you to COH everywhere!

- Why it is important for the media to address Hoarding Disorder in a realistic way - by Elizabeth Nelson

Hoarding behaviour happens in a lot of different situations that present many different challenges. Some people are receptive to help, some people are not. For some people, the disorder already threatens their health and safety, for other people it is just an embarrassing problem. In the ongoing research and
study of how to address this problem, how best to treat it, there are several informed and legitimate perspectives.

Professionals come to the table with the experience of having treated individuals who can recognize a problem. Hoarders in recovery offer the perspective of individuals who both recognize the problem and want to seek help. Our organization is important because our perspective is based on a much wider range of experience. As a group of COH, we understand and have lived with every conceivable type of hoarding behaviour. We are impacted wherever and however hoarding behaviour happens. Only family members can report on those circumstances of hoarding where the individual is most isolated and removed from any potential help or treatment.

There are two reasons why honest and accurate media attention is so important. The most important reason, I think, is that the public needs to understand the issue as one of mental health rather than lifestyle choice. Presented in a non-exploitive way, the ugliest aspects of this disorder can highlight an important truth: this behaviour is not a character flaw or sign of weakness, it is a symptom of illness for which people need medical treatment. Secondly, it reduces the stigma when as much "truth" about the illness can be revealed and publicized. For years, the only glimpse of "hoarding" revealed in the media (especially on television) came in very tidy packages, with smiling faces and happy endings. These depictions were very disheartening for the vast majority of our membership, whose situations looked nothing like that. Accurate and more complete information is better for everyone who feels the shame and isolation of living with this, both impacted family members and compulsive hoarders. When media attention is inaccurate or always spins the same (limited) kind story, many are left wondering if *anyone* else out there could possibly be struggling in the same way.

It would have been a great comfort to me, as a child, to have even the slightest awareness that other families lived with the same problem. As my mother's illness has progressed, I often wonder how things might have turned out differently for her, too. She is nearly 80 years old and she matter-of-factly tells us that she is too old to change. What if, in 1960, she could have read an article about hoarding, recognized herself in the early stages of the disorder? Would she have been more willing to seek help? I believe so. I believe that *many* people in the early stages of this disorder will be more likely to seek help simply because they see themselves in the media. Without that chance to see themselves or hear a story that defines the behaviour as a problem, those habits get stronger and stronger. Over time, the shame and embarrassment
only gets worse and as the problem gets bigger the excuses get bigger, too. My hope is that as the media gets better and better at including more voices, more various perspectives on this disorder, none of us will need to feel so ashamed about and isolated by the experience.

- **Children of Hoarders Perspective from the UK** - by Rose Edmunds

At present, there is much less awareness of hoarding in the UK than in the US, and in particular the impact of hoarding on children is seldom aired in the public domain. However, this is beginning to change and it is refreshing to see a public figure such as Jasmine Harman coming out the child of a hoarder. Her documentary 'My Hoarder Mum and Me' which aired on BBC1 last August provided a fascinating insight into her life and her mother's condition. With others, I have recently formed a UK support group for COH and we meet every few months. At present the group is very small but the therapeutic value of bonding with others in the same situation is immense.

For my own part, obviously I would rather not have grown up in the shadow of my mother's hoarding. However, I recently jumped off the corporate hamster wheel to become a writer and have found that my unusual childhood is providing an interesting angle for the book I am currently writing, where the heroine struggles to deal with her hoarding mother as well as trying to unravel a complex web of corruption! My first novel, Never Say Sorry, which came out recently does not deal with hoarding directly, but I believe that as a result of my experiences I have been better able to articulate the isolation and anxieties of my key protagonists.
HOARDING PODCAST

- **Podcast about Hoarding** – Interview with Dr. David Mataix-Cols from King’s College London with some interesting information about hoarding, available online at [http://soundcloud.com/volen/david-mataix-cols-podcast-1](http://soundcloud.com/volen/david-mataix-cols-podcast-1)

PhD student and psychologist Volen Ivanov from the Department of Clinical Neurosciences at Karolinska Institute in Sweden interviews Dr. David Mataix-Cols, an expert in hoarding research who is working at King’s College London. During the podcast, Dr. Mataix-Cols explains the symptoms of hoarding and talks about his research findings suggesting hoarding should be included as a new diagnosis ("hoarding disorder") in the upcoming medical classification system (DSM-V). Moreover, Dr. Mataix-Cols answers questions about the potential causes of hoarding and how hoarding can be treated. Enjoy this exciting podcast!

CONFERENCE ON HOARDING AND CLUTTERING

- **14th International Conference on Hoarding and Cluttering, taking place from 26/04/2012 to 27/04/2012 in San Francisco (USA)**

We were excited to find out that a hoarding conference took place recently in San Francisco (USA). The so-called “14th Annual International Conference on Hoarding and Cluttering” is a multidisciplinary event that draws together stakeholders and experts across fields. The conference focuses on solutions to the personal and community burdens that arise from hoarding problems. The event has been organised by the Mental Health Association of San Francisco and brought together clinicians, advocates and individuals living with hoarding issues into one place for learning, sharing and developing approaches to the complex issues around the disorder. We hope that we might be lucky enough to find some presentations of this conference online soon so that we can all benefit a little bit from this brilliant event! We really need a hoarding conference in the UK, too!