### Table 3. Patient-reported facilitators of coping

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<th>Theme</th>
<th>Representative Quotes</th>
<th>Targets for interventions</th>
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| Meeting others & online support           | “Though I have a loving family I had spent most of my life feeling depressed, confused, lonely, alone, isolated, and frequently in despair. In just a couple of hours at the meeting 3 years ago... those feelings decreased. For the first time ever I was with a group of people with whom I felt normal and at ease, valued and respected. This has made a tremendous difference in my life.”  
• “It wasn’t until I found other people like (patient community leader) that I kind of filled in the blanks a bit. It was quite isolating for me and I had no one to talk to and I felt like I was the only person in the world to have this problem”  
• “I’ve really felt alone. So I went online, on Facebook just to see if there was something or a meeting and I found this group and it was the best thing I ever did because I found out there are other people and I thought I was alone. But I found others... which is really good”  
• “Going to my first Kallmann (CHH) meeting about 6 years ago… and until then, I was totally in the dark. And when I met up with fellow patients, I realized I’m not on my own”  
|                                            |                                                                                                                                                                                                                     | online peer-to-peer support               |
|                                            | “Get over it, take matters into your own hands… you will get help. All you have to do is ask for it. (To the moderator) in your research, you are searching for ways that would help me… a booklet, a fact sheet ‘living with Kallmann (CHH)’ that kind of thing…it also involves emotional things. If you can give that to a doctor so then that is the trigger to start a conversation. Then you can take matters into your own hands”.  
• “So it was a change in mentality, being taunted as a child then I realized that I had to do certain things to get my life back”  
• “It was just the things that I would have to find out about myself that no one could tell me... and like I said, (patient community leader) has helped... Both on a personal level and for the research into the condition itself. But, being able to live with it is a very personal thing that I think you need to find out for yourself...and I think I’m coming along pretty nicely... I’m not letting it rule my life quite so much as I used to.”  
|                                            |                                                                                                                                                                                                                     | patient empowerment                       |
| Positive healthcare interactions           | “All the medical professionals I have been working with…I’ve been very lucky because they have always been very helpful and considerate about it. So, I guess I have been fortunate that way”  
• “Definitely, self-injecting (helped). Learning about the syndrome made me feel that Kallmann (CHH) is not such a big deal. But in my case, it was not enough... and the psychotherapy aspect helped a lot”  
• “I first heard about Kallmann’s (CHH) at 25 when I moved in a new city and changed endocrinologists. That made a huge difference, suddenly she made it sounds like it was not such a big deal. In my experience female doctors are more easy to talk with, tend to ask more about how it works in the everyday life, and involve us in our prescriptions”  
|                                            |                                                                                                                                                                                                                     | promoting patient-centered approaches & developing a “talking sheet” to initiate discussions with providers |

* Quotes referencing the term “Kallmann’s” refers to Kallmann syndrome - the association of CHH with the inability to smell (anosmia)*