

# Health Care Transition of Adolescents and Young Adults with Haemophilia: the Situation in Germany and the Munich experience

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## Abstract

Patients suffering from haemophilia encounter various phases in life, in which individual needs, life situations, and self- and disease perception change rapidly. One of these phases spans from the beginning of puberty until early adulthood, in which individuals gain self-responsibility and reach independence and autonomy. In this challenging time that determines future health, adolescents and young adults need sustainable familiar and professional support. A change in health care team and treatment centre may expose adolescent patients to threats but also provides the possible opportunity to be well prepared. While there is emerging evidence that the so-called health care transition programmes are effective in maintaining quality of care in other disease areas, transition programmes for patients with haemophilia are still rare in Germany, and the evidence is limited. We describe the situation in Germany, discuss our experience in Munich and review some of the available guidance; we conclude that transition programmes should become a standard of care in haemophilia.

## Keywords

- haemophilia
- transition
- medical
- psychosocial

## Zusammenfassung

Patienten mit Hämophilie durchlaufen verschiedene Lebensabschnitte, in denen sich ihre Bedürfnisse, Lebensumstände und ihr Blick auf die Erkrankung und sich selbst verändern. Eine dieser Phasen umfasst die Pubertät und den Übergang ins Erwachsenenalter. In dieser Zeit erlangen die Patienten Eigenverantwortung und streben nach Unabhängigkeit und Autonomie. Diese Phase ist herausfordernd und bestimmend für die gesundheitliche Zukunft. Daher benötigen die Patienten eine tragfähige familiäre und professionelle Unterstützung, um Ängsten zu begegnen und mögliche Chancen herauszuarbeiten. Die Effektivität von Transitions-Programmen wird bereits für viele Krankheitsbilder in der Literatur beschrieben, allerdings werden diese im Bereich der Hämophilie in Deutschland selten angewendet. Wir beschreiben die Situation in Deutschland, erläutern unsere Münchner Erfahrungen und besprechen einige der verfügbaren Empfehlungen aus der Literatur. Zusammenfassend sollten Transitions-Programme Teil der Routinebehandlung bei Hämophilie werden.

## Schlüsselwörter

- Hämophilie
- Transition
- medizinisch
- psychosozial

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## Introduction

Haemophilia is an inherited, lifelong bleeding disorder resulting from a deficiency of clotting factor VIII or IX. Due to its X-chromosomal inheritance pattern, males are almost exclusively affected, suffering from a markedly enhanced bleeding tendency correlated with the severity of the disease. While some patients show bleeding as early as in the neonatal period, most patients with severe haemophilia will present with an unusual haematoma as toddlers. Later, the bleeding pattern is correlated with the patient's mobility and activity. If joint bleeds occur, they might lead to joint damage and immobility as a sequela. The risk of bleeding affects the patient's everyday life, e.g. admission to and activity in kindergarten, school and sports activities. To allow a widely normal life while protecting joint health, prophylactic treatment with clotting factor concentrates<sup>1</sup> has been employed as the standard of care. This treatment has led to a better quality of life in patients, and new alternative non-factor treatment strategies might even improve the situation.

## Transition in Chronically Ill Young People

The time of puberty and adolescence represents a period of developmental tasks, vulnerability and opportunities, and is associated with medical, biological and emotional changes. Although not generally a time of great stress and fragility for all,<sup>2</sup> young people might experience a high level of insecurity while reaching for autonomy and independence, building identity and gaining increasing amounts of responsibility.

For chronically ill adolescents and young adults (AYAs), all of the typical problems of teenagers apply, but the health status of ill juveniles is especially at risk – first, because of the stress imposed by the disease, leading to a higher vulnerability and a higher risk to develop psychosocial problems,<sup>3</sup> and second, due to an often decreasing adherence to therapy or problems in self-management. Parents, peers and professional caregivers can help to guide patients through this process.<sup>4</sup>

The change of the medical treatment centre for AYAs with a chronic disease might be a risk but also a chance to ensure the future quality of treatment in these patients.

## Health Care Transition Programmes: Evidence and Guidelines

Health care transition (HCT) programmes aim at reducing these potential dangers and improving quality of care by a holistic and structured education and guidance of the patients and their families.<sup>5–7</sup>

The Cochrane Study Group searched for studies and relevant reviews on the topic of transition<sup>8</sup> and identified four randomized controlled trials that met the inclusion criteria, covering a limited range of interventions,<sup>9–12</sup> but not including haemophilia. Although there was some evidence for a positive impact, the current studies' database was too limited to draw firm conclusions on the effectiveness of the evaluated interventions and the certainty of the body of evidence from these studies was low.

A recent and systematic literature review on this topic<sup>13</sup> identified 43 (out of 3,844 articles) publications that met their evaluation criteria. Positive outcomes due to a structured transition approach comprised an improvement in adherence, improved perceived health status, quality of life and self-care skills plus increased adult visit attendance, and less time between the last paediatric visit and the initial adult visit.

However, due to the lack of detailed descriptions of transition interventions, it is still not possible to link specific transition interventions to outcomes.<sup>6,13</sup>

Despite this lack of randomized controlled trials and sometimes heterogeneous results, structured HCT programmes are internationally accepted as an important part of regular medical care, and various consensus statements and guidelines (e.g. diabetes,<sup>14</sup> congenital heart disease<sup>15</sup> or cystic fibrosis<sup>16</sup>) list similar core elements of these programmes.

Exemplarily, the American Academy of Pediatrics (AAP) recommendations define nine principles of HCT,<sup>6</sup> which mainly focus on recognizing the AYA patient as a newly self-responsible person and providing knowledge and tools to support these individuals in caring for themselves: (1) focus on the young individual, (2) emphasis on self-responsibility but also the possible support, (3) acknowledgment of the patient's individuality, personal strengths and differences, (4) recognition of the special needs of this age group, (5) an early HCT start that continues into young adulthood, (6) shared responsibility of paediatric and adult caregivers, (7) consideration of cultural beliefs and socioeconomic status, (8) necessity to achieve health care equity and (9) support of parents and caregivers to build up the patient's knowledge and decision-making capacity. It is also important to acknowledge that the chronic disease affects not only the patient but also his parents and siblings, i.e. the family system as a whole,<sup>17</sup> and that, for example, parental anxiety might even interfere with the transition process.<sup>18</sup>

In conclusion, HCT programmes are an area of increasing interest and importance,<sup>19</sup> despite the lack of evidence from randomized controlled trials.<sup>7</sup>

## Transition in Adolescents and Young Adults with Haemophilia

We conducted a PubMed search for 'transition' AND 'haemophilia OR hemophilia' AND 'randomised OR randomized' but identified no documents that matched the search terms. Replacing 'randomised OR randomized' by 'studies' we found 44 documents, most of them not focusing on specific HCT programmes for patients with haemophilia but on the age group in general (e.g. Valentino et al<sup>20</sup>), treatment adherence (e.g. Schrijvers et al<sup>21</sup>), caregiver impact,<sup>22</sup> and possible studies<sup>23</sup> and outcome indicators of HCT programmes.<sup>24</sup>

However, these studies together with the above-reviewed experience in HCT from other disease areas support the need for education and transition programmes, joint paediatric/adult clinics, and special youth and transition clinics.<sup>25</sup>

As outlined above, the medical and therapeutic life of a patient with haemophilia is a life in transition from birth to

adulthood concerning mobility, disease activity, therapy, social life and perception.<sup>25</sup> As in other chronic diseases, families and patients benefit from health care support during this process, allowing optimal preparation and advice.<sup>26</sup>

Therefore, the 'National Hemophilia Foundation of the United States' implemented transition guidelines in 2003,<sup>27</sup> quoting the work of Mary C. Paone in stating that 'The goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate and psychologically sound prior to and throughout transfer into the adult system'.<sup>28</sup> The relevance of this goal has been underlined by an early study, showing that the stress level of patients with haemophilia is higher and the quality of life is lower in the post-transition era.<sup>29</sup>

### Medical Aspects of Transition in Patients with Haemophilia

When discussing the coming life changes and the problems faced by our patients, multiple questions and key problems are raised; medical, psychosocial and legal aspects are involved.

It is crucial that patients with haemophilia understand their medical condition, possible barriers and treatment options available. At this age, patients should be able to perform home treatment by themselves and to act in the case of bleeding. This skill and the swap from parent care to self-care are the key to independence<sup>29</sup>; e.g. to allow studying abroad, patients must be able to substitute factor concentrates at work or while travelling. Patients also need to know about complications during their course of disease, possible physical impairments and pain management in patients who already have affected joints and consecutive arthrosis.

At a time with increasing numbers of alternative treatment options arising, only educated patients will be able to judge their current treatment and to decide whether they are willing to change treatment or enter clinical trials, which are far more often available to adult patients than to children. There is evidence that taking into account AYA needs and preferences when planning treatment enhances adherence to prophylactic treatment.<sup>30</sup> Patients often do not consider themselves to be 'ill' as they have few limitations in life. This good outcome is often the result of successful therapy, and patients might not be aware that further treatment adherence is necessary to maintain a good medical status.<sup>31</sup>

### Psychosocial Aspects of Health Care Transition in Haemophilia

Several psychosocial aspects affected by the diagnosis of haemophilia have been described.<sup>32</sup> As in healthy children, peer acceptance is very important. This includes the possibility of sharing the diagnosis with friends. AYAs with haemophilia aim for the perception of being normal. For some, activities such as youth camps provide relief, allowing them to pair up with AYAs with the same problems. Regarding the coming changes of care, young patients are often unsure about adult care.<sup>33</sup> Many have known their paediatric haemophilia centre since birth and have now to face new doctors. A gradual

transfer of responsibilities, both in medical care and in self-care (in comparison to being looked after by parents), will improve outcome.<sup>24</sup> Additionally, the change from school to university or work raises many questions. What job to choose, where to live and how to care for oneself are all questions that are also asked by healthy adolescents; however, these questions are strongly influenced by the imposed and perceived barriers in AYAs with haemophilia. Some guidance might be found on web sites that focus on jobs and haemophilia, e.g. [www.berufe-haemophilie.de](http://www.berufe-haemophilie.de).<sup>34</sup> Additionally, many questions around the 'disabled person' status arise. The identification of disabled persons and the laws regulating the compensation for those with disabilities could be seen as a benefit, but it also imposes fear on AYAs because some employers might hesitate to employ a person with haemophilia. Therefore, social law counselling and job interview training are a necessary part of the HCT. Being abroad, travelling the world and taking a year off are common wishes of AYAs after finishing school; again, attaining these goals might be influenced by haemophilia.<sup>35</sup> Finally, partnership and sexuality are issues that are rarely discussed during a regular consultation but have a great impact on our patients.<sup>36</sup>

### The Situation for Transition in Patients with Haemophilia in Germany

In 2015, the 'Standing Commission Paediatrics' of the German Society of Thrombosis and Haemostasis Research (Gesellschaft für Thrombose und Hämostaseforschung, GTH e.V.) initiated a survey amongst its members to examine the current status and availability of HCT programmes in haemophilia care in Germany.<sup>37</sup> Out of 45 member centres in Germany, 33 responded (73%), 13 of these fulfilled the criteria of a comprehensive care centre, 15 were haemophilia treatment units (Hämophilie Behandlungseinheiten, HBE) and 5 were smaller haemophilia units (Hämophilie Behandler, HB). Fifteen centres were specialized paediatric haemophilia centres, and 18 centres treated both children and adults. A regular transition program was in place in only four centres (13%). At least one joint clinic with paediatric and adult physicians was held in nine centres (27%). Sixteen centres (48%) reported that they do accompany the transition, but not in a standardized manner; in four centres (12%), no options for transition assistance were available. Interestingly, these findings were not correlated with the type or size of the treatment centres. This short survey showed, impressively, that, despite their long-accepted relevance, transition programmes for haemophilia treatment in Germany were still rare and less coordinated than in other countries or in other disease areas as of 2015.

### Experience from Munich

Although working closely together, both the paediatric and adult haemophilia treatment centres of the University of Munich are independent. Children are treated only by paediatricians in the children's hospital.

Until 2010, AYAs with haemophilia were referred rather randomly from the paediatric haemophilia centre, Munich,

to the adult centre. In many cases, patients were just released to the adult department with a discharge summary. Some patients were treated in the paediatric centre until their late 20s, illustrating both the wish of the patients and, sometimes especially, their parents, for continuity in health care providers; in addition, the paediatricians sometimes have difficulty letting go of 'their' patients, a phenomenon previously described in a position paper of the Society for Adolescent Medicine in 1993.<sup>18</sup>

New regulations by insurance companies and a new hospital policy in Munich driven by limited resources have led to a stricter referral of patients to the adult department on their 18th birthday since 2010. Although it is not required by law to transfer adult patients for outpatient visits to the adult department, this transfer was necessary e.g., for practical reasons to ensure adequate inpatient care when needed, since adult patients with haemophilia were no longer allowed admission to our paediatric hospital.

However, although this upcoming event was discussed on some paediatric centre visits, the process of leaving paediatric care raised anxiety in both patients and parents, since they felt inappropriately prepared for this change.

To ease this rather abrupt change and to optimize the transfer of medical information, patients are often accompanied by one of their well-known paediatricians for their first visit to the adult department. However, this one joint paediatric and adult clinic fulfils merely the basic criteria of a structured, adequate HCT program.

## Starting a Structured Transition Program in Munich

Therefore, together with our colleagues from the adult department, we aim to optimize the transition process and have started a transition program in 2019. Instead of just one joint paediatric/adult clinic, the program consists of several visits, begins with puberty and spans into early adulthood, as recommended by most authors in the field (e.g. White and Cooley<sup>6</sup>). However, there is no fixed age, as the right time for transition always depends on the individual situation of the patient.<sup>26</sup>

From January to September 2019, three patients were enrolled in the structured HCT program, with two transition appointments (see ▶Table 1) by now. Five patients aged 16 years and older have participated in a shortened program, where we have provided information on the disease, independence, social law and career choice during one to three additional appointments. Although our program is at its start and has not been evaluated yet, the feedback from both patients with haemophilia and caregivers was positive. For the future we plan to offer the structured HCT program to all our patients.

As a first step, the parents are asked to leave the room for some time during the appointment when the patients are approximately 14 years of age. This happens often during the physical examination by the paediatrician and the physiotherapist, allowing some privacy for the patient and giving room for a trustful talk between the patient and his profes-

sional caregivers. At the next appointment, a first transition appointment is scheduled with the patient, his parents, the physician and a social worker. Until the actual transition, transition issues are always part of the regular appointments. According to the needs and preferences of the patient, these discussions will be private or together with the parents or other health care providers.

To ensure a holistic approach, we now use the documentation tool shown in ▶Table 1. Similar documents have been developed at the Ludwig Maximilian University (LMU) Centre for Development and Complex Chronic Diseases in Children (iSPZ Hauner) by the divisions of rheumatology, gastroenterology and diabetes and are in regular use for the transition of their patients. Studies using this tool are ongoing at the iSPZ Hauner, but no data have yet been published.

Common barriers during the HCT have been described.<sup>33</sup> In ▶Table 2, we show how we attempt to conquer these barriers in the transition process of young people with haemophilia. Since the transition reaches from paediatric to adult care, the key element to overcome these barriers is a close and visible collaboration between paediatric and adult haemophilia caregivers and, if possible, to allow patients to experience the regional haemophilia caregivers as a team. Of course, a joint haemophilia centre for both paediatric and adult patients assembling the individual expertise of specialized physicians would probably help to overcome bureaucratic barriers.

## Further Information to Start a Structured Transition Process

The American Society of Hematology has created a 'Haemophilia Transition Readiness Assessment Template', consisting of both a self-assessment completed by the AYA and a medical assessment and epicrisis completed by the physician.<sup>38</sup> This tool, covering disease knowledge, medication management, insurance and privacy issues but also the level of confidence of the patients to cope with their disease, is very helpful in determining areas of special needs for each individual prior to transition.

The web site 'got transition' ([www.gottransition.org](http://www.gottransition.org)) offers many resources, focusing on the 'Six Core Elements of Health Care Transition', which are as follows: (1) installing a transition policy; (2) tracking and monitoring transition; (3) evaluating readiness for transition; (4) planning transition; (5) transferring of care and (6) completing the transition. Available in English and Spanish, this web site offers many suggestions on how to implement a transition program.

More ideas on how to support youth with chronic diseases can be found in an article from members of the very active 'transition' working group of the German Society of Rheumatology.<sup>39</sup> Although focused on AYAs with rheumatic disease, many of the proposed services could be adopted for patients with haemophilia.

More information reflecting the situation in Germany can also be found on the web site of the German Society of Transition Medicine (Gesellschaft für Transitionsmedizin, GfTM e.V., [www.transitionsmedizin.net](http://www.transitionsmedizin.net)).

**Table 1** Pathway, topics and documentation for the transition of AYAs with haemophilia at Munich Haemophilia Centre

First discussion with adolescents and parents (paediatrician, clinical psychologist, social worker)
<input type="checkbox"/> Aim of transition process = <i>self-responsibility and autonomy in disease-related aspects</i> <input type="checkbox"/> Evaluation and acknowledgment of parent's efforts and accomplishments <input type="checkbox"/> Autonomy, self-responsibility <input type="checkbox"/> Topics to discuss (i.e. medical knowledge, therapy, education/job, transition to adult caregivers) <input type="checkbox"/> From next appointment: start alone, parents join later
Medical knowledge (paediatrician)
<input type="checkbox"/> Diagnosis <input type="checkbox"/> Comorbidities, infectious diseases <input type="checkbox"/> Orthopaedic problems, sports, sport injuries <input type="checkbox"/> Genetics of the disease, family history <input type="checkbox"/> Course of the disease, acute and chronic complications, sequelae <input type="checkbox"/> Medication: name, dose, frequency, home self-therapy, mechanism of action, prior drugs, complication, further developments <input type="checkbox"/> Emergencies, emergency treatment <input type="checkbox"/> Laboratory values <input type="checkbox"/> Sexuality, genetics <input type="checkbox"/> Vaccinations: route of administration, risks, missing vaccinations <input type="checkbox"/> Alcohol, smoking, drugs
Changing treatment teams (paediatrician, clinical psychologist, social worker)
<input type="checkbox"/> Process of appointment: history, questions, examination, prescriptions <input type="checkbox"/> Differences in adult treatment: time, self-responsibility, expectations, medication, examinations <input type="checkbox"/> Medical letter, doctor's wording <input type="checkbox"/> Finding a new physician, expectations, how to deal with disappointment
Coping with the disease (clinical psychologist)
<input type="checkbox"/> Autonomy, self-responsibility <input type="checkbox"/> Successful home self-therapy? Barriers? <input type="checkbox"/> Self-perception of being chronically ill. Blame? Guilt? <input type="checkbox"/> Peer group, friends, best friends, family <input type="checkbox"/> Social system: caregivers, attachment figures <input type="checkbox"/> Information: instruction leaflet, NGOs, patient initiatives, internet resources <input type="checkbox"/> Hobbies, sports <input type="checkbox"/> Dealing with social pressure <input type="checkbox"/> Dealing with alcohol, drugs <input type="checkbox"/> Sexuality and partnership
Social law (social worker)
<input type="checkbox"/> Moving, travel, working and studying abroad <input type="checkbox"/> School, university or job, choosing a job <input type="checkbox"/> Insurance, additional costs, additional treatments <input type="checkbox"/> Disability ID, disability compensation, case of hardship, social law, employment law <input type="checkbox"/> Disease-specific problems
Complete transition (paediatrician, adult physician, social worker, clinical psychologist)
<input type="checkbox"/> Decision on new treatment centre <input type="checkbox"/> Next appointment in adult treatment centre <input type="checkbox"/> Prepare discharge summary and discuss with patient <input type="checkbox"/> Contact adult physician <input type="checkbox"/> Confirm joint clinic with adult physician <input type="checkbox"/> Hold joint clinic in adult treatment centre <input type="checkbox"/> Ensure delivery of new emergency card, emergency numbers

Abbreviations: AYAs, adolescents and young adults; NGOs, non-governmental organizations.

## Future Outlook

HCT programmes are also there in the field of vision for health care politicians and cost payers. Several German insurance companies have started transition programmes together with the German professional organization of paediatricians (Berufsverband der Kinder und Jugendärzte, BVKJ e.V., [www.bvkj.de](http://www.bvkj.de)). Although none of these programmes currently include

haemophilia, some programmes plan to widen the list of indications in the near future. These programmes focus on medical practitioners, but they are the first in Germany to actually address the issue of public reimbursement of transition programmes, which might help haemophilia centres while discussing costs with insurance companies.

Of course, HCT programmes should be monitored and regularly evaluated. The French haemophilia network has



**Table 2** The most commonly reported barriers to successful transition as reported in Gray et al<sup>33</sup> and the solutions already in place or planned at Munich Haemophilia Centre

Barrier	Solutions at Munich Haemophilia Centre
Relationships between patient, paediatrician and paediatric team	<ul style="list-style-type: none"> <li>• Joint clinic with adult team</li> <li>• Joint patient activities for children, adolescents, adults and parents</li> </ul>
Beliefs/expectations	<ul style="list-style-type: none"> <li>• Structured transition plan</li> <li>• Connect to young adults with haemophilia who have already finished the process of transition               <ul style="list-style-type: none"> <li>– That is, summer camp ('Chiemseefreizeit' of the German Haemophilia Society [Deutsche Hämophilie Gesellschaft, DHG e.V.])</li> <li>– AYA visits to parent-patient weekends of the Bavarian advisory service for people with bleeding disorders (Bluter Beratung Bayern, BBB e.V.)</li> </ul> </li> <li>• Tour through adult clinic</li> </ul>
Skills/efficacy	<ul style="list-style-type: none"> <li>• Start transition early and regularly</li> <li>• Provide education and training (related to medical and therapeutic topics as well as social law)</li> <li>• Provide training on self-management, home treatment and dealing with emergencies</li> <li>• Encourage independent visits or visits where at least some time is spent without parents</li> <li>• Use of new technologies to involve adolescents in their treatment, such as electronic diaries or tools to calculate individual pharmacokinetics</li> <li>• Regular evaluation of transition readiness</li> <li>• Close collaboration between teams</li> </ul>
Access	<ul style="list-style-type: none"> <li>• Transition specialist (social worker)</li> <li>• Use of biopsychosocial resources of the iSPZ Hauner</li> </ul>

Abbreviations: AYA, adolescents and young adults.

addressed the issue of HCT in patients with haemophilia and initiated a prospective study to elucidate the haemophilia transition (TRANSEMO, ClinicalTrials.gov Identifier: NCT02866526). The study aims for results by December 2019 and will hopefully add evidence to the sparse knowledge on HCT in patients with haemophilia.<sup>23</sup>

For AYAs with malignant and haematological diseases, the 'Working Group on Adolescents, Young Adults, and Transition (Arbeitsgemeinschaft Adoleszenten, junge Erwachsene, Transition, AjET)' has been established within the Society for Paediatric Oncology and Haematology (GPOH). This group intends to build a national, multidisciplinary network to increase awareness of the topic and to define and evaluate standards of care. Some members of this group will focus on AYAs with inherited bleeding disorders.<sup>40</sup>

## Conclusion

In conclusion, a structured HCT program has been shown to be effective for AYAs in many disease areas. Although there is not yet much evidence in haemophilia, it seems clear that adequate planning and a program providing education and a structured transition will improve medical care and outcomes. We hope that, by these joint efforts of paediatric and adult caregivers, this important step in independence and self-responsibility will be comfortable and successful for our patients. While the Munich HCT program has just started and has not been evaluated by now, material such as the provided documentation tool might be of interest for other centres. We conclude that structured transition programmes for

AYAs should become part of the standard of care for patients with haemophilia.

## Conflicts of Interest

Dr. Bidlingmaier reports personal fees from Biotest, personal fees from CSL Bering, personal fees from Novo Nordisk, other from Roche, personal fees from Bayer, personal fees from Sobi, personal fees from Shire, outside the submitted work; Dr. Bidlingmaier is PI of the German Paediatric Haemophilia Research Database. GEPHARD receives funding from Bayer, Biotest, CSL Behring, Intersero, Octapharma, Sobi, Pfizer, Shire/Takeda, Grifols and Novo Nordisk.

Dr. Olivieri reports personal fees from Sobi, personal fees from Pfizer, personal fees from Biotest, personal fees from Takeda, personal fees from Bayer, personal fees from Novo Nordisk, grants and personal fees from CSL Behring, personal fees from Octapharma, personal fees from Grifols, outside the submitted work.

Dr. Kurnik reports grants and personal fees from Bayer, personal fees from Biotest, personal fees from CSL Behring, personal fees from Novo Nordisk, personal fees from Roche, personal fees from Sobi, personal fees from Shire/Takeda, outside the submitted work.

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