



Growth Hormone  
Deficiency

**KNOW  
YOUR  
RIGHTS**

*A resource for people with growth hormone deficiency and their loved ones.*

August 2023

 **AIMED ALLIANCE**

COVERAGERIGHTS.ORG



## OVERVIEW

While many individuals will not have problems with their body's production of growth hormone, some individuals can develop either an underproduction of growth hormone or an overproduction of growth hormone. When an individual's body is unable to produce the appropriate amount of growth hormone, they may have a condition known as "growth hormone deficiency."<sup>1</sup> Alternatively, when an individual's body overproduces growth hormone, they may have a condition known as "acromegaly" or "gigantism."<sup>2</sup>

While these conditions are caused by separate problems with the body's production of the growth hormone, the barriers to their treatment can often be similar. Barriers may include overly burdensome benefit utilization policies, challenges receiving coverage for long-acting injections, and difficulties in receiving medical necessity coverage for non-formulary treatments.

This resource specifically focuses on growth hormone deficiency. If you are interested in learning more about the overproduction of growth hormone, please read our Know Your Rights resource, available [here](#).



# UNDERPRODUCTION

## Growth Hormone Deficiency

Growth hormone deficiency (GHD) is a rare condition in which the pituitary gland does not produce enough human growth hormone (hGH).<sup>3</sup> GHD can be present at birth (congenital) or develop later (acquired).<sup>4</sup> In children, GHD is characterized by short stature with normal body proportions. Even after childhood growth is complete, growth hormones are needed to help maintain normal body structure, including fat, muscle, tissue and bone; and regulate metabolism, including insulin levels and blood glucose levels.<sup>5</sup> In adults, GHD causes a variety of issues, including increased body fat, cholesterol, and blood sugar levels, and can lead to complications like increased risk of stroke or heart attack.<sup>6</sup> Approximately, one in 4,000 to 10,000 children have growth hormone disorder.<sup>7</sup>

### Symptoms

The primary symptom of GHD in children is slow height growth each year after a child's third birthday.<sup>8</sup> Other symptoms of GHD in children and infants include: a younger-looking face for their age; impaired hair and nail growth; delayed tooth development; delayed puberty; and low blood sugar levels.<sup>9</sup>

Adult-onset GHD can be more difficult to detect, but symptoms may include reduced sense of wellbeing; anxiety and/or depression; decreased energy levels; increased body fat, especially around the stomach; decreased muscle tone; decreased bone density; insulin resistance; and increased LDL-cholesterol and triglyceride levels.<sup>10</sup>

### Diagnosis

GHD often includes an analysis of height and growth patterns, along with blood tests.<sup>11</sup> Growth hormone is made in short bursts, mostly overnight, making them difficult to measure.<sup>12</sup> Therefore, practitioners may order a blood test to measure an insulin-like growth factor 1 (IGF-1) and an IGF binding protein 3 (IGFBP-3). Jointly these two proteins are markers of growth hormone functioning.<sup>13</sup> Health care providers

may also order a growth hormone stimulation test (GHST), which involves fasting before the administration of Arginine, an IV medication that causes the body to produce a burst of growth hormone, thereby allowing health care providers to assess the individual's growth hormone levels.<sup>14</sup> Other methods of diagnosis can include x-rays to conduct a radiographic assessment of bone age or a brain MRI.<sup>15</sup> For some individuals, test results may not clearly indicate there is a growth hormone deficiency, therefore, it is important parent and caregivers continually consult with their child's health care provider to monitor their growth and development.

GHD should be diagnosed and treated early, to optimize growth and increase the potential for successful medical intervention and positive health outcomes.<sup>16</sup> However, GHD is often diagnosed later in childhood.<sup>17</sup> Factors contributing to delays in diagnosis include the low performance of available diagnostic testing,<sup>18</sup> lack of public education, and late referrals to an endocrine specialist.<sup>19</sup> As a result, patients may miss the window for growth hormone treatments to be effective.<sup>20</sup> Delays in treatment may lead to shorter stature (height) and delayed puberty. For adults, the risk of heart disease, bone fractures and anxiety may worsen.



## Disparities in Diagnosis and Treatment

GHD affects males and females equally; however, males are more likely than females to be screened and treated for GHD by primary care physicians.<sup>21</sup> Additionally, white male children are referred more often for short stature (SS) evaluation, and proceed more frequently with growth hormone testing when compared to minority groups and females.<sup>22</sup> Among many considerations, this gender difference may be attributable to societal stigmas surrounding male height, and to differences in growth, with males typically reaching adult height later in life.<sup>23</sup> Furthermore, societal misconceptions that taller males are more “masculine”<sup>24</sup> and “dominant” may also contribute to primary care physicians testing males more often than females.<sup>25</sup>

## Treatment Options

Treatment for GHD involves receiving regular injections of synthetic growth hormone. These injections can be administered via daily or weekly injections.

For some caregivers, daily injections can be difficult due to a child's dislike of injections, inability to stay still, or other conflicts that can make it difficult to maintain treatment compliance.<sup>26</sup> Thus for some patients, long acting injectables may improve treatment adherence and alleviate the burden of chronic daily injections, which can be painful and distressing.<sup>27</sup> However, insurance companies often do not approve a weekly treatment, over a daily treatment, for convenience. If a weekly treatment is more suitable for a patient's individual needs, patients should emphasize the improvement in quality of life when talking to practitioners or insurance companies. Whether through daily injections or weekly injections, proper treatment adherence is critical to effective GHD treatment and ultimately health outcomes.<sup>28</sup>

## Consequences of Not Treating GHD

The consequences of not treating GHD in children extend beyond short stature and delayed puberty.<sup>29</sup> Growth hormone regulates metabolism, body composition, and cardiovascular health, helping maintain physical performance, general well-being, and quality of life.<sup>30</sup> If left untreated in children and adults, it can lead to the risk of high cholesterol, heart disease, and poor heart and lung strength.<sup>31</sup> Long-term, untreated GHD in adults is also linked to reduced cardiac output and exercise capacity; insulin resistance; increased abdominal fat mass; and reduced muscle mass and bone mineral density.<sup>32</sup> Forgoing treatment can also have detrimental psychological effects.<sup>33</sup> For instance, one study found that discontinuation of treatment in adults with severe GHD resulted in decreased energy and increased fatigue, pain, irritability, and depression.<sup>34</sup> For children with untreated GHD, one study found an increased risk of anxiety, depression and other psychiatric diseases.<sup>35</sup>

## Meeting Your Cost Sharing Requirements

Health plans may have high-cost sharing requirements for some treatments. If you are concerned about the cost of you or your child's medication, you may be eligible for third-party assistance. Third-party assistance comes in multiple forms including manufacturer copay-assistance programs, patient assistance programs for uninsured or underinsured patients, and charitable assistance programs. However, some of these programs have income and condition requirements and, therefore, you will need to determine whether you meet the program eligibility criteria. In addition, if your health plan has adopted a copay accumulator policy, this third-party assistance will not count towards meeting your cost-sharing requirements.



Health insurers use a variety of practices that may delay or deny access to your treatment for your growth hormone deficiency. To find out whether your insurer may have improperly delayed or denied access to your treatment, ask yourself the following questions:



## **STEP THERAPY**

***Did my insurer make me try a different treatment before covering the growth hormone deficiency medication or therapy that my care team originally prescribed?***

This practice is called “step therapy” or “fail first” because it requires patients to try other treatments first and demonstrate that they do not work or are intolerable before the health plan will cover the originally prescribed treatment. Your insurer may require you to try and fail on multiple different treatments before covering the one prescribed by your care team.<sup>36</sup> This can lead to delays in access to medically necessary treatment, which in turn, can result in disease progression. Step-therapy is not recommended in any treatment guidelines for growth hormone. Treatment guidelines for GHD also do not recommend switching between long-acting growth hormone and daily growth hormone injections as they are not therapeutically equivalent.

Step therapy policies may violate federal or state laws if your insurer treats you and others with similar diagnoses differently because of your health condition. In addition, some states have passed legislation to limit the type of step therapy protocols that can be used. For instance, some state laws prohibit trying and failing on more than one treatment, failing on a treatment you have already tried and found ineffective, or failing on an off-label treatment. Additionally, you may also be entitled to an exception from the step therapy process.



## **NON-MEDICAL SWITCHING**

***Is my insurer forcing me to take a different medication, even though my current treatment is working, by refusing to cover it any longer or increasing my copay?***

This practice is referred to as “nonmedical switching.” It occurs when your insurer (not your health care professional or pharmacist) forces you to switch from your current treatment to a different (but not a generic equivalent) treatment by either refusing to cover your drug therapy any longer or increasing the out-of-pocket cost of your treatment.<sup>37</sup> Nonmedical switching can result in relapse and disease progression. One study found that when patients were nonmedically switched, over 75 percent of them experienced side effects as a result of the switch.<sup>38</sup> In addition, nonmedical switching may violate certain states' consumer protection laws.<sup>39</sup>

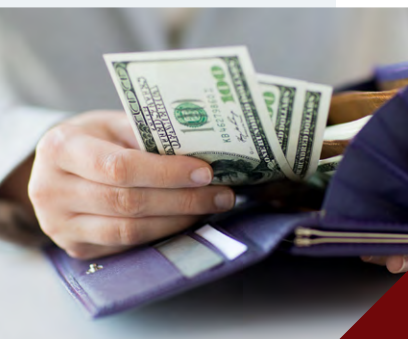




## PRIOR AUTHORIZATION

*Do I need to get my insurer's approval before I can begin or continue my prescribed growth hormone deficiency treatment or therapy?*

This practice is called "prior authorization." It happens when your insurer requires you or your doctor to get your insurer's approval before the treatment or therapy is covered. Approval is based on the insurer's standards, which may be inconsistent with medical standards of care and harmful to patients. For those living with a growth hormone deficiency the results can be devastating. These policies can also violate state and federal laws if applied in a certain manner.



## ADVERSE TIERING

*Do I have to pay a high copay for certain medications that treat my condition?*

This practice is called "adverse tiering." It can be used by insurers to shift much of the cost for newer or innovative therapies to patients by placing expensive drugs on what are called "specialty tiers." Certain tiering policies may also violate certain federal and state laws if used in a discriminatory way.<sup>40</sup>



## COPAYMENT ACCUMULATORS

*If I receive coupons or discounts to help pay for my medication copays, does my insurer prohibit those coupons or discounts from counting toward my annual deductible?*

This policy is known as a "copayment accumulator." Copayment accumulators force patients to pay more out of pocket when copayment assistance runs out and the insurance deductible has not been met. These policies are frequently buried in the fine print of insurance contracts and may violate state consumer protection laws.<sup>41</sup> In addition, 16 states have passed laws that prohibit health plans from implementing copayment accumulators.



## "EXPERIMENTAL-TREATMENTS"

*Has my treatment recently been approved by the FDA and my insurer has denied coverage because it considers the treatment "experimental"?*

In general, an insurer may deem a treatment experimental if it determines that the treatment is not the standard of care for a particular condition.<sup>42</sup> Experimental treatments may include non-FDA-approved treatments, those that lack substantial evidence to support their medical effectiveness, and off-label treatments.<sup>43</sup>

## My insurer refuses to cover a growth hormone deficiency treatment or therapy that my health care professional prescribed to me. **What can I do?**

If your insurer refuses to cover your treatment, here are three steps you can take to try to change your insurer's decision:

- Appeal the decision;
- Request an external review; or
- File a consumer complaint.



### How do I appeal the decision?

If your insurer denies your claim, you have the legal right to an internal appeal.<sup>44</sup> This means you can ask your insurer to conduct a full and fair review of its decision. To appeal the denial, you should do the following:



**Review the determination letter.** Your insurer should have sent you a determination letter to tell you that it would not cover your claim. Review this document so you can understand why your insurer denied your claim and how you can appeal the denial.



**Collect information.** Collect the determination letter and all other documents the insurance company sent you. This includes your insurance policy and your insurer's medical necessity criteria. "Medical necessity criteria" refers to your insurer's policy for determining whether a treatment or service is necessary for your condition.<sup>45</sup>



**Request documents.** If you did not receive the determination letter or do not have your policy information, the medical necessity criteria, or the instructions and forms for filing an appeal, call the insurer's customer service representative and ask for these documents. The company website will list the toll-free telephone number to call.



**Submit the appeal request.** It is important for you or your health care professional's office to submit the appeal request as soon as possible along with the letter from the health care professional and all additional information the insurer requested.



**Once you file an appeal request, expect to wait up to 30 days to hear back from the insurance company regarding a treatment you hope to receive.** It can take up to 60 days for a response if you received the treatment and are waiting for reimbursement.



**Follow up.** Follow up with your insurer regularly until you hear back. Be sure to keep a record of the name of any representative you speak with about the appeal, the date and time you spoke with that person, a confirmation number for the call, and a summary of your discussion.



**Call your health care professional's office.** The health care professional's office or clinic has people on staff to help with the external appeal process. They will tell you how to fill out the forms to request an appeal, write an appeal letter on your behalf, or handle the appeal request for you.



## How do I tell my insurer the treatment my health care provider prescribed is not experimental?

You should ask your insurer for a written statement of the exact reasons for the denial (i.e., why the treatment is considered experimental), if that information has not already been provided. Review your plan documents carefully to see how the plan defines “experimental” (or “investigational” or “unproven”) treatment. These terms can vary from plan to plan.

The FDA will only approve a treatment if there is evidence that the treatment is safe and effective. Therefore, if your treatment has recently been approved by the FDA and is indicated for your condition, then you may be able to appeal the denial on the basis that it is no longer “experimental.” If you are being prescribed an FDA-approved treatment off label (i.e., it is not indicated for your condition), review your plan documents closely. Some plans have exceptions for coverage of FDA-approved off-label treatments for certain disorders if specific conditions are met.<sup>46</sup>

## What if my insurer denies my appeal?

Insurance companies often deny that growth hormone is necessary based on outdated research; however, growth hormone is necessary for supporting proper growth, regulating metabolism and maintaining health body composition and cardiovascular health. Under law, you are entitled to take your appeal to an independent third party for an “external review,” which means the insurance company no longer gets the final say over whether to approve a treatment or pay a claim. The situation applies if the insurer denies your appeal or if your medical situation is urgent and waiting would jeopardize your life or ability to function.

## How do I request an external review?

To trigger an external review, you must file a written request for an external review within four months after the date you receive a notice or final determination from your insurer that your claim has been denied.<sup>47</sup> The process should take no more than 60 days. However, in urgent situations requiring an expedited review (i.e. in cases of panhypopituitarism), the process should take no longer than four business days. To find out whom to contact in your state to request an external review, please go to [www.CoverageRights.org](http://www.CoverageRights.org).





## How do I file a complaint?

If your insurer denies your coverage after the external review process, you can file a complaint with the insurance commissioner or attorney general in your state. To determine whom to contact and how to submit the complaint, please go to [www.CoverageRights.org](http://www.CoverageRights.org)

Your complaint should include the following information:

- The name, address, email address, and telephone number of the person filing the complaint ("Complainant");
- The name of the insured individual, if different from the Complainant;
- The names of any other parties involved in the claim (for example, the plan administrator or pharmacy benefit manager);
- The name of the insurance company and the type of insurance;
- The state where the insurance plan was purchased;
- Claim information, including the policy number, certificate number, claim number, dates of denial, and amount in dispute;
- The reason for and details of the complaint; and
- What you consider to be a fair resolution.

You should also submit the following supporting documents with your complaint:

- A copy of your insurance card;
- Copies of coverage denials or adverse benefit determinations from your insurer;
- Copies of any determinations made by internal and external reviewers;
- Any materials submitted with prior appeals and complaints;

- Supporting documentation from your health care professional;
- A copy of your insurance policy; and
- All responses from your insurer.

## What happens after the state insurance commissioner or attorney general receives my complaint?

The insurance commissioner or attorney general will assign someone to research, investigate, and resolve your complaint. That person will examine your account, records, documents, and transactions. He or she may question witnesses, request additional documents from other parties, and hold a hearing. If the insurance commissioner or attorney general determines that the insurer violated laws or regulations, he or she may order the insurer to give you the requested coverage or compensate you.

## Whom should I call if I have any questions about filing a complaint?

To determine whom to call in your state, please visit [CoverageRights.org](http://CoverageRights.org).

## Other helpful resources:

[The Magic Foundation](#) – The Magic Foundation is a charitable non-profit organization created to provide support services for the families of children afflicted with a wide variety of chronic and/or critical disorders, syndromes and diseases that affect a child's growth. The Magic Foundation has developed resources specific for individuals navigating a claim denial for growth hormone therapy and injections. View their resources [here](#).



## REFERENCES

1. Endocrine Society, Growth Hormone Deficiency, <https://www.endocrine.org/patient-engagement/endocrine-library/growth-hormone-deficiency>.
2. Anna Boguśławska and Márta Korbonits, Genetics of Acromegaly and Gigantism, <https://www.mdpi.com/2077-0383/10/7/1377>.
3. Endocrine Society, Growth Hormone Deficiency, <https://www.endocrine.org/patient-engagement/endocrine-library/growth-hormone-deficiency>.
4. Endocrine Society, Growth Hormone Deficiency, <https://www.endocrine.org/patient-engagement/endocrine-library/growth-hormone-deficiency>.
5. Donatella Capalbo, Growth Hormone Improves Cardiopulmonary Capacity and Body Composition in Children With Growth Hormone Deficiency, <https://academic.oup.com/jcem/article/102/11/4080/4096781>.
6. Donatella Capalbo, et al., Growth Hormone Improves Cardiopulmonary Capacity and Body Composition in Children With Growth Hormone Deficiency, <https://academic.oup.com/jcem/article/102/11/4080/4096781>.
7. Camille Hage et al., Advances in differential diagnosis and management of growth hormone deficiency in children, <https://www.nature.com/articles/s41574-021-00539-5>.
8. Cleveland Clinic, Growth Hormone Deficiency, [https://my.clevelandclinic.org/health/diseases/23343-growth-hormone-deficiencyghd#:~:text=Growth%20hormone%20\(GH\)%20acts%20on,your%20body%20still%20needs%20GH.\(Jan.24,2022\)](https://my.clevelandclinic.org/health/diseases/23343-growth-hormone-deficiencyghd#:~:text=Growth%20hormone%20(GH)%20acts%20on,your%20body%20still%20needs%20GH.(Jan.24,2022)).
9. Id.
10. Id.
11. Takara Stanley et al., Diagnosis of Growth Hormone Deficiency in Childhood, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3279941/>.
12. Ursula Kaiser and Ken K.Y. Ho, Chapter 8 - Pituitary Physiology and Diagnostic Evaluation, <https://www.sciencedirect.com/science/article/abs/pii/B9780323297387000083>
13. Takara Stanley et al., Diagnosis of Growth Hormone Deficiency in Childhood, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3279941/>
14. Id.
15. Yuen KCJ, Growth Hormone Stimulation Tests in Assessing Adult Growth Hormone Deficiency, <https://www.ncbi.nlm.nih.gov/books/NBK279055/?report=reader>.
16. International Coalition of Organizations Supporting Endocrine Patients (ICOSEP), Global Endocrine Network, <https://www.icosep.org/>; Endocrine Society, Growth Hormone Deficiency, <https://www.endocrine.org/patient-engagement/endocrine-library/growth-hormone-deficiency>.
17. Morey Haymond, Anne-Marie Kappelgaard, Paul Czernichow, Beverly MK Biller, Koji Takano, Wieland Kiess, Early recognition of growth abnormalities permitting early intervention, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3738943/>.
18. Takara Stanley, Diagnosis of Growth Hormone Deficiency in Childhood, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3279941/>.
19. Mohamad Maghnie, Jose I Labarta, Ekaterina Koledova, and Tilman R. Rohrer, Short Stature Diagnosis and Referral, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5768898/>.
20. Aetna, Growth Hormone (GH) and Growth Hormone Antagonists, [https://www.aetna.com/cpb/medical/data/100\\_199/0170.html](https://www.aetna.com/cpb/medical/data/100_199/0170.html).
21. OHSU, Growth Hormone Deficiency, <https://www.ohsu.edu/brain-institute/growth-hormone-deficiency>.
22. Kara Beliard, Vickie Wu, Julie Samuels, Terri H. Lipman, and Roveert Rapaport, Identifying and addressing disparities in the evaluation and treatment of children with growth hormone deficiency, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9448989/>.
23. Karger, The Boy: Girl Ratio of Children Diagnosed with Growth Hormone Deficiency-Induced Short Statute Is Associated with the Boy: Girl Ratio of Children Visiting Short Stature Clinics, <https://www.karger.com/Article/Abstract/518995>.
24. Huter Holzeitner, et al., Men's facial masculinity: when (body) size matters, <https://research-repository.st-andrews.ac.uk/handle/10023/6681>.
25. Carlota Batres, Daniel E. Re, & David I. Perrett, Influence of Perceived Height, Masculinity, and Age of Each Other and on Perceptions of Dominance in Male Faces, <https://journals.sagepub.com/doi/pdf/10.1177/0301006615596898>; David E Sandberg & Linda D. Voss, The psychosocial consequences of short stature: a review of the evidence, <https://reader.elsevier.com/reader/sd/pii/S1521690X02902113?token=A42E8C9FA0C558C1B596FD96AB747B430B0F18E12FBC91A1BDBC06EC98932B8D3E5BFD23C22BEC320D21870B32427715&originRegion=us-east-1&originCreation=20230323160134>.
26. Nadine van Dongen & Ad A Kaptein, Parents' views on growth hormone treatment for their children: psychosocial issues, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3422117/>; see also Carrie Madormo, Coping with Pediatric Growth Hormone Deficiency, <https://www.verywellhealth.com/coping-with-pediatric-growth-hormone-deficiency-5116710>.
27. Loftus J, et al., Caregiver Burden In Daily Human Growth Hormone Injections for Children, [https://www.valueinhealthjournal.com/article/S1098-3015\(17\)32474-9/fulltext](https://www.valueinhealthjournal.com/article/S1098-3015(17)32474-9/fulltext).
28. Kevin C. J Yuen, Bradley S. Miller, Cesar L. Boguszewski, & Andrew R. Hoffman, Usefulness of Potential Pitfalls of Long-Acting Growth Hormone Analogs, <https://www.frontiersin.org/articles/10.3389/fendo.2021.637209/full>.
29. Marlene Busko, FDA Approves First Once-Weekly Growth Hormone for Children, <https://www.medscape.com/viewarticle/958043>.
30. Meryl Brod, Suzanne Lessard Lolga, Jane F. Beck, Lars Wilkinson, Lise Hojbjerg, & Michael Hojby Rasmussen, Understanding burden of illness for child growth hormone deficiency, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5486907/>.
31. Donatella Capalbo, et al., Growth Hormone Improves Cardiopulmonary Capacity and Body Composition in Children With Growth Hormone Deficiency, <https://academic.oup.com/jcem/article/102/11/4080/4096781>. Donatella Capalbo, et al., Update on early cardiovascular and metabolic risk factors in children and adolescents affected with growth hormone deficiency, <https://www.minervamedica.it/en/journals/minerva-endocrinology/article.php?cod=R07Y2012N04A0379>; Alessandro Ciresei and Carla Giordano, Glucose Metabolism in Children With Growth Hormone Deficiency, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6005337/>; Donatella Capalbo, et al., Growth Hormone Improves Cardiopulmonary Capacity and Body Composition in Children With Growth Hormone Deficiency, <https://academic.oup.com/jcem/article/102/11/4080/4096781>.

32. Gudmundur Johannsson & Oskar Ragnarsson, Growth hormone deficiency in adults with hypopituitarism—What are the risks and can they be eliminated by therapy, <https://onlinelibrary.wiley.com/doi/full/10.1111/joim.13382>.
33. C.V. McMillan, C. Bradley, J. Gibney, L. Healy, D. L. Russell-Jones, & P.H. Sonksen, Psychological effects of withdrawal of growth hormone therapy from adults with growth hormone deficiency, <https://onlinelibrary.wiley.com/doi/abs/10.1046/j.1365-2265.2003.01870.x?sid=nlm%3Apubmed>.
34. Id.
35. İsmail Akaltun, et al., Is growth hormone deficiency associated with anxiety disorder and depressive symptoms in children and adolescents?: A case-control study, <https://www.sciencedirect.com/science/article/pii/S1096637418300480#:~:text=Children%20with%20growth%20hormone%20deficiency,social%20life%2C%20and%20depressive%20symptoms>.
36. Aimed Alliance, Step-Therapy, <https://aimedalliance.org/step-therapy/>.
37. Aimed Alliance, Non-Medical Switching, <https://aimedalliance.org/nonmedical-switching/>.
38. Patients Rising Now, Fighting Nonmedical Switching, <https://patientsrisingnow.org/fighting-nonmedical-switching/>; Endocrine News, The Year in Endocrinology, [https://endocrinenews.endocrine.org/wp-content/uploads/EN1217\\_INT-web.pdf](https://endocrinenews.endocrine.org/wp-content/uploads/EN1217_INT-web.pdf).
39. Promoting Access to Affordable Prescription Drugs: Policy Analysis and Consumer Recommendation for State Policymakers, Consumer Advocates, and Health Care Stakeholders, [https://advocacy.consumerreports.org/wp-content/uploads/2016/08/Promoting-Access-to-Affordable-Prescription-Drugs\\_Aug-2016.pdf](https://advocacy.consumerreports.org/wp-content/uploads/2016/08/Promoting-Access-to-Affordable-Prescription-Drugs_Aug-2016.pdf).
40. Douglas Jacobs & Wayne Turner, Nondiscrimination And Chronic Conditions – The Final Section 1557 Regulation, <https://www.healthaffairs.org/doi/10.1377/forefront.20160720.055888/full/>.
41. Aimed Alliance, Copay Accumulators, <https://aimedalliance.org/copay-accumulators-map/#AZ>.
42. See, e.g., BlueCross BlueShield of North Carolina, Corporate Medical Policy, [https://www.bluecrossnc.com/sites/default/files/document/attachment/services/public/pdfs/medicalpolicy/investigational\\_experimental\\_services.pdf](https://www.bluecrossnc.com/sites/default/files/document/attachment/services/public/pdfs/medicalpolicy/investigational_experimental_services.pdf).
43. See, e.g., United Healthcare, Experimental/Investigational Treatment and Acquire Rare Disease Drug Therapy Exception Process, <https://www.uhcprovider.com/content/dam/provider/docs/public/policies/oxford/experimental-investigational-tx-ohp.pdf>.
44. How to appeal an insurance company decision, Healthcare.gov, <https://www.healthcare.gov/appeal-insurance-company-decision/appeals/> (last visited July 19, 2018).
45. Am. Medical Assoc., Survey: Patient clinical outcomes shortchanged by prior authorization, <https://www.ama-assn.org/press-center/press-releases/survey-patient-clinical-outcomes-shortchanged-prior-authorization> (Mar. 19, 2018). See also e.g., N.M. Admin. Code. 13.10.17.7 (2018). Complaint to Federal Government Agency: Patient, Legal Action Center, <https://lac.org/wp-content/uploads/2016/04/10-Patient-Federal-Complaint.docx> (last visited July 19, 2018).
46. See, e.g., United Healthcare, Off-Label/Unproven Specialty Drug Treatment, <https://www.uhcprovider.com/content/dam/provider/docs/public/policies/comm-medical-drug/off-label-unproven-specialty-drug-treatment.pdf>.
47. Healthcare.gov, Appealing a health plan decision, <https://www.healthcare.gov/appeal-insurance-company-decision/external-review/>.



**1455 Pennsylvania Avenue NW, Suite 400 • Washington, DC 20004**  
**202-349-4089 • AimedAlliance.org**

© 2023 Aimed Alliance. All Right Reserved.