

**Effective October 1, 2023, ALSP will have an ICD 10 Code.**

**Know Your Code...G93.44 for ALSP**

### **ALSP Community: What can YOU do to help?**

It is critical that doctors, other healthcare providers, and their teams use the new code for ALSP, every time they see an ALSP patient. Patients can help by telling all their healthcare providers about the new code and encouraging other families to do the same. Ask your healthcare providers to spread the word to their colleagues, too.

Healthcare providers:

- Use the code for your patients at every healthcare encounter
- Share this information with your networks
- Notify your coding team

### **Frequently Asked Questions About ICD Codes**

#### **What is an ICD code?**

ICD stands for “International Statistical Classification of Diseases and Related Health Problems.” It is a standard classification system used around the world throughout the healthcare system and by government agencies and researchers to track and report diseases, disorders, injuries, and other health conditions.

The ICD coding system is maintained by the World Health Organization (WHO) and has roots dating back to 1893. It has gone through 11 major revisions over that time. The US and 150 other countries currently use ICD-10; ICD-11 will be available on January 1, 2022. However, migration to a new ICD revision occurs at different rates across the world and can take several years to fully implement. There is no mandatory deadline for adoption and the previous version will remain in effect until the new one is adopted by a given country.

**ICD Code Fun Fact:** *ICD-10 was approved by WHO in 1992, but it didn’t go into effect in the US until 2015.*

#### **Why do ICD codes matter?**

ICD codes are like a “lubricant” in the enormous global healthcare and biomedical research enterprise. Accurate and appropriate ICD codes help information move more swiftly and smoothly through the system. As [described by the WHO](#), maintenance and use of this standard classification systems allows for:

- Easy storage, retrieval and analysis of health information for evidenced-based decision-making
- Sharing and comparing health information between hospitals, regions, settings and countries
- Data comparisons in the same location across different time periods

Consider the power of understanding which types of medical specialties are diagnosing a particular rare disease or having the ability to track changes in patients' health outcomes after a new therapy is approved for their disease. A payer's medical policy decisions for a new therapy might be based on an assessment of how many individuals covered by their plans have a particular diagnostic code in their record. These are the types of queries made possible through ICD codes. They are also the types of assessments that can be distorted by imprecise or out-of-date codes.

### **What do ICD codes mean to my life?**

Every encounter you have with the healthcare system is documented through the use of ICD codes (for diagnoses and symptoms) and their cousins (CPT and HCPCS codes for procedures, services, drug, devices, vaccines, etc.). The way these codes are combined can affect whether and how much an insurance company or other payer will reimburse for that encounter. If a condition doesn't have an appropriate ICD code, the physician will choose from existing codes for other conditions which could affect coverage and reimbursement for the care you receive. This also makes it hard to accurately trace the outcomes of that care since it isn't linked to the specific condition for which it was provided, nor will you be recognized in the data system as having that condition. Finally, in the diagnosis process, physicians may be less likely to consider conditions without an ICD code.

### **Who should be interested in ICD codes?**

The ICD system is carefully tended by dedicated professionals around the world. While anyone affected by or interested in health-related issues has reason to know about ICD codes, the subject is most important to people affected by or interested in diseases and health conditions for which improper (or lack of) classification adds to the burdens experienced by affected patients, caregivers, and healthcare systems. By helping draw attention to the public health-related need for coding updates and developing solid evidence to support an addition or change to a specific coding structure, you can be part of the worldwide effort to support better research and care.

***ICD Code Fun Fact:*** *If you are (or become) passionate about ICD codes, you can get certified and find your fellow "code geeks" through organizations like the [American Health Information Management Association](#).*

### **How can I find out whether the disease I'm interested in has an ICD code?**

There are numerous public databases online, so start by entering "ICD code for [disease/condition of interest]" into any search engine. The results of that search may take you to descriptions that are used for different purposes, such as a "billable diagnostic code," and may show how that disease/condition is "indexed" to other disease and injury classifications. It may also yield a description of the code's history – how it has changed over time – and other conditions with which that code is associated. You may need to seek the advice of medical and/or scientific advisors to determine whether the classification as it currently exists is appropriate. With the ever-evolving scientific understanding of the human body and diseases of all types, it's impossible for the ICD to be fully up to date.

If you don't get any results on your first search, try searching a few different ways (especially for diseases that may go by several names) on different search engines before concluding that the condition of interest doesn't have a code. If you still come up empty, consult a few physicians with expertise in your disease/condition of interest about whether a specific code exists and/or how they code for that diagnosis. This is important

information you will definitely need to have if you embark on a code proposal. (See “How do new codes get added or codes get revised?” below.)

You can also search the [“pre-release” version of the ICD-11](#) to see if the disease you’re interested in is reflected in it; ICD-11 will start going into effect in 2022. (See “What is an ICD code?” above for more information.)

If you are searching for an ICD code for a rare or genetic disease and determine there is not one, make sure the disease is recognized in the National Institutes of Health’s Genetic and Rare Disease (GARD) listing of rare diseases. This is an important first step before attempting to secure a new ICD code.

**ICD Code Fun Fact:** For the fiscal year ending 9/30/20, there were 72,184 unique ICD-10 codes in the US version of the system known as ICD-10-CM. [ref](#)

### **How do new codes get added or codes get revised?**

As you might anticipate, an international standardized classification system is built for endurance rather than speed. At the international level, WHO is responsible for maintaining and updating the ICD. In the US, maintenance of diagnostic codes is the responsibility of the National Center for Health Statistics (NCHS), part of the Centers for Disease Control and Prevention (CDC). **Procedure** codes fall under the remit of the Centers for Medicare and Medicaid Services (CMS).

Updates are managed by the [ICD-10 Coordination and Maintenance Committee](#), a joint effort of NCHS and CMS. Codes are updated annually in October of each year based on proposals and evidence submitted and carefully reviewed over the previous 18-24 months. The Committee bases its decisions for code updates on the strength of evidence presented, including a public health-related reason for the change, sound rationale for the proposed code restructuring, and demonstrated consensus among experts that it is warranted. They will also evaluate whether there might be unintended consequences of a proposed coding change, including how it might impact tracking for conditions linked to the existing and proposed codes. As you’re likely beginning to appreciate, altering the code is a delicate matter that must be approached with diligence and care.

**ICD Code Fun Fact:** In the fiscal year ending 9/30/20, 273 codes were added, 21 were deleted, and 30 were revised. [ref](#)

### **What role can patient advocacy organizations play in updating ICD codes?**

If it is suspected or determined that the manner in which a disease or condition is represented in ICD warrants reconsideration, patient advocacy organizations can play a central role in bringing together the various stakeholders whose expertise and experience may be needed to develop an evidence-based proposal to present to the ICD-10 Coordination and Maintenance Committee. Several patient advocacy organizations have led successful initiatives to add new ICD codes or revise existing codes. It takes partnership, persistence, and patience, but it can be done!

**ICD Code Fun Fact:** Learn more about some of the patient advocacy organizations that have participated in ICD code updates by checking out the case studies below.

### **Where can I learn more about getting involved in the process of updating an ICD code?**

You’re in luck! The EveryLife Foundation has created an ICD Code Roadmap to help patient advocacy leaders and their partners understand, evaluate their role, and navigate the process. In addition to this FAQ, please make use of these resources and feel free to share them widely:

- [How ICD codes Impact the Rare Disease Community Journey](#): A lively, 2-minute animated video useful for sharing with Board members, medical and scientific advisors, volunteers and others whom you may want to help better understand the process
- [Readiness Assessment Survey](#): This tool provides a set of questions and self-ratings to help patient advocacy leaders assess their readiness to engage in the ICD code revision process and highlights capabilities that can improve chances for success
- [ICD Code Roadmap Resource Guide](#): This guide provides detailed information about the process and links to websites and other helpful resources

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