



Privacy Policy & UK GDPR Compliance Notice

Effective Date: June 18, 2026

1. Introduction and General Provisions

The **NKX6-2 Cure Initiative** respects your privacy and is fully committed to protecting your personal data. This privacy notice informs you how we look after your personal data when you visit our website (regardless of where you visit it from) and outlines your privacy rights and how the law protects you within the United Kingdom.

This platform serves as a centralized hub for scientific research compilation, gene therapy updates, and communication pathways connecting medical professionals, scientists, patients, and their families. It is financed fully by our anchor funder as disclosed across our structural footers.

We act as the **Data Controller** for all processing operations occurring across this domain. We have appointed an administrative lead responsible for overseeing questions in relation to this privacy notice.

2. The Data We Collect About You

Personal data, or personal information, means any information about an individual from which that person can be identified. It does not include data where the identity has been removed (anonymous data). We may collect, use, store, and transfer different kinds of personal data about you, grouped as follows:

A. General Personal Data

- **Identity Data:** First name, last name, title, or professional clinical credentials (if interacting as a healthcare provider or researcher).
- **Contact Data:** Email address, telephone numbers, and operational location/country.
- **Technical Data:** Internet protocol (IP) address, browser type and version, time zone setting and location, browser plug-in types, operating system, and platform.
- **Usage Data:** Information about how you navigate and use our website, scientific publication library, and clinical resource zones.

B. Special Category Data (Health & Genetic Profiles)

⚠ CRITICAL COMPLIANCE NOTICE (UK GDPR Article 9): Because this platform investigates gene therapy for a rare genetic condition (NKX6-2), users utilizing our "Let's Connect" form or interactive Q&A submission tools may choose to voluntarily submit **Special Category Data**. This includes explicit details regarding patient medical histories, symptomatic progression, diagnostic statuses, genetic mutations, and historical or active clinical trial involvements.

We will only collect and process this Special Category Data when you provide your **explicit, affirmative, opt-in consent** via our dedicated submission checkboxes. We only know what you choose to tell us. We never track your health data behind the scenes.

3. Lawful Bases for Processing

Under the UK GDPR, we must establish a valid legal justification to handle your data. The primary frameworks we rely upon are mapped in the matrix below:

Processing Activity	UK GDPR Standard Basis (Article 6)	Article 9 Condition (Special Category Data)
Navigating the site / Web Analytics	Legitimate Interests (To optimize platform security and resource deployment).	Not applicable (No health profiles or patient statuses are processed passively).
Enquiries via "Let's Connect" Forms	Explicit Consent	Article 9(2)(a): Explicit and affirmative opt-in consent of the data subject.
Scientific Library Research Queries	Legitimate Interests (To provide public access to compiled scientific texts).	Not applicable.

4. How We Use Your Personal Data

We use your data strictly inside non-commercial, operational parameters. Specifically, we process it to:

- Administer and protect this digital platform (including troubleshooting, data analysis, testing, system maintenance, and support).
- Respond to direct clinical, research, or personal questions submitted through our communication channels.
- Route information seamlessly to coordinate connections between clinicians, international laboratories, and affected families—**only** when requested explicitly by you.

We will **never** sell, lease, monetize, or share your data with advertising or corporate tracking networks.

5. Disclosures & International Transfers

Because the NKX6-2 community is global, we coordinate with world-class specialists across multiple geographical territories. If you request that we introduce you to an international clinical team or research group based outside the United Kingdom (e.g., in the US or EU), your data will be transferred across borders.

When international data transfers occur out of the UK, we ensure a similar degree of protection is afforded to it by ensuring at least one of the following safeguards is implemented:

- We will only transfer your personal data to countries that have been deemed to provide an adequate level of protection for personal data by the UK Government.

- Where we use certain service providers or share data with international researchers, we utilise specific **International Data Transfer Agreements (IDTAs)** or Standard Contractual Clauses (SCCs) approved for use in the UK which afford personal data the exact same protections it has within the UK.

6. Data Security

We have put in place robust technical and administrative security measures to prevent your personal data from being accidentally lost, used, or accessed in an unauthorised way, altered, or disclosed.

In addition, we limit access to your personal data to those employees, agents, research coordinators, and contractors who have a legitimate operational need to know. They will only process your personal data on our direct, written instructions, and they are bound by strict legal duties of confidentiality.

7. Data Retention

We will only retain your personal data for as long as reasonably necessary to fulfil the purposes we collected it for, including for the purposes of satisfying any legal, regulatory, or reporting requirements.

If you request the removal of your connection record, your identity and special category data will be completely deleted or securely anonymised within 30 days of your identity validation.

8. Your Legal Rights Under UK GDPR

Under certain circumstances, you have comprehensive rights under UK data protection laws in relation to your personal data:

- **Request access** to your personal data (commonly known as a "data subject access request").
- **Request correction** of the personal data that we hold about you.
- **Request erasure** of your personal data where there is no operational justification for us continuing to process it.
- **Object to processing** of your personal data where we are relying on a legitimate interest framework.
- **Request restriction of processing** of your personal data.
- **Request the transfer** of your personal data to you or to a chosen third party.
- **Withdraw consent at any time** where we are relying on consent to process your personal data (especially regarding Article 9 Special Category health data).

9. Contact & Supervisory Authority

If you wish to exercise any of the rights set out above, or have a question about this policy, please contact us directly at: dvs@dvsproperty.com

You also hold the absolute right to make a complaint at any time to the **Information Commissioner's Office (ICO)**, the UK independent supervisory authority for data protection issues (www.ico.org.uk). We would, however, deeply appreciate the opportunity to address your concerns and resolve the issue before you approach the ICO, so please contact us in the first instance.