



## **HDBuzz 2025 Annual Report**

Prepared February 2026 by Rachel Harding and Sarah Hernandez

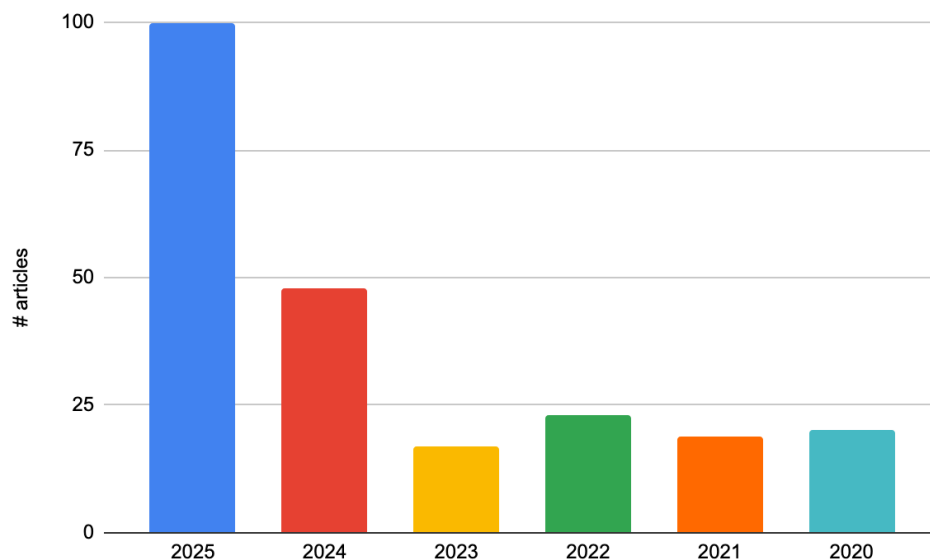
## HDBuzz Report - 2025

### 1. Executive Summary

2025 marked the most ambitious and transformative year in HDBuzz's history. Under the leadership from Dr. Sarah Hernandez and Dr. Rachel Harding, HDBuzz:

- Published a record 100 articles, doubling output from 2024 to a consistent twice-weekly schedule (Mondays and Thursdays). **(Fig.1)**
- Expanded its writing team, bringing in contributors from leading research institutions.
- Launched a new social media platform (LinkedIn) and expanded presence on others (Facebook, X, Bluesky, Instagram).
- Formed an advisory board and completed its transition to an independent 501(c)(3) nonprofit.
- Revitalised mentorship initiatives, including the HDBuzz Prize for Young Science Writers and partnership with HDF's HD-CAG program.
- Ran two major community-driven fundraising campaigns to reinforce independence from pharmaceutical funding.

This year positioned HDBuzz to advance as a mature, independent, globally-engaged science communication organisation serving the Huntington's disease (HD) community during a period of accelerating therapeutic development and increasing clinical complexity.



**Figure 1.** Number of articles published annually from 2020 through 2025.



## 2. Mission and Vision Update

HDBuzz exists to deliver clear, accurate, unbiased reporting on HD research, accessible to families, clinicians, researchers, and advocates worldwide.

In 2025, this mission was advanced through:

- Real-time reporting from major scientific conferences.
- Clear interpretation of complex therapeutic developments, including regulatory shifts.
- Transparent coverage of both promising advances and setbacks (e.g., AMT-130 developments and regulatory challenges).
- Sustained commitment to independence from pharmaceutical funding.

2025 set the stage through legal, administrative, and logistical preparation so that HDBuzz could realize a long-standing goal of organisational independence. HDBuzz officially became a standalone 501(c)(3) nonprofit as of January 1, 2026, through efforts from 2025 entailing the establishment of independent governance, formation of an advisory board, and continued policy of never accepting pharmaceutical funding.

As HD research approaches potential disease-modifying therapies, the need for unbiased interpretation has never been greater. 2025 positioned HDBuzz as the trusted intermediary between rapid scientific progress and community understanding.



### 3. Operational Review - 2025

#### A. Content Production and Editorial Growth

*Output:*

- 100 articles published (record year). **(Fig. 1)**
- Transitioned from ~2 articles/month to twice-weekly publication.

*Coverage spanned:*

- HTT-lowering strategies
- Genetic modifiers and DNA repair
- Biomarker development
- CRISPR delivery systems
- Neuroimaging and EEG biomarkers
- Mental health interventions
- Mechanistic biology and therapeutic targeting

*Team Expansion:*

- Expanded writing team by 6 to include contributors from leading research institutions.
- Diversified perspectives and expertise across the HD field.
- Hired a social media manager to broaden reach.

#### B. Mentorship and Pipeline Development

A defining focus of 2025 was investing in the next generation of HD scientists and communicators.

1. The HDBuzz Prize for Young Science Writers (Sponsored by the Huntington's Disease Foundation (HDF))

The 2025 Prize returned to train early-career researchers, including PhD students, postdocs, early-stage investigators, and clinicians, in accessible science communication. Prize winners received \$200 USD for their contributions to HDBuzz.

*Goals:*

- Diversify scientific voices.
- Train researchers in community-facing communication.
- Energise coverage with fresh perspectives.

*2025 Prize Winners and Topics:*



- **Mustafa Mehkary** (University of Toronto, Canada) - Expanded HTT disrupts DNA repair, creating a damaging feedback loop.
- **Eva Woods** (Trinity College Dublin, Ireland) - EEG biomarkers showing pre-symptomatic brainwave differences.
- **Jenna Hanrahan** (Memorial University in Newfoundland, Canada) - MRI findings linking structural brain changes to anosognosia.
- **Nicolo Zarotti** (Manchester Centre for Clinical Neurosciences and the University of Leeds) - Acceptance and Commitment Therapy improving well-being in HD dyads.
- **Gravity Guignard** (University of Toronto, Canada) - Risks of lowering "good" HTT in therapeutic development.
- **Chloe Langridge** (Marquette University, USA) - SGTA as a potential therapeutic target.

These articles demonstrated scientific rigor paired with accessibility, reinforcing the program's value.

## 2. HD-CAG Partnership (HDF)

HDBuzz partnered with the inaugural HD-CAG (Huntington's Disease Career Advancement Grant) program to mentor senior postdoctoral researchers transitioning to independence.

2025 HD-CAG Awardees:

- **Sonia Vasquez-Sanchez** (UCSD; mentored by Don Cleveland)
- **Chris Kay** (UBC; mentored by Michael Hayden)
- **Shota Shibata** (Harvard; mentored by Ricardo Mouro Pinto)
- **Devon Pendlebury** (UC Irvine; mentored by Leslie M. Thompson)
- **Piere Rodriguez-Aliaga** (Stanford; mentored by Judith Frydman)

HDBuzz provided science communication mentorship and published their work, strengthening both community literacy and early-career development.

This represents a strategic investment in the long-term intellectual and communicative strength of the HD field.

## C. Conference Reporting

HDBuzz continued to provide real-time coverage from major scientific meetings on Bluesky that was later aggregated into articles published on hdbuzz.net and shared on all social media platforms.

*CHDI Therapeutics Conference (February 2025, Palm Springs)*

- 400+ scientific experts
- Clinical updates on HTT-lowering approaches



- Advances in DNA repair and genetic modifiers
- Biomarker validation
- CRISPR delivery technologies

*HD Clinical Research Congress (HSG) (October 2025, Nashville)*

- New trial designs and endpoint refinement
- Early-phase therapeutic results
- Community-researcher alignment
- Data sharing strategies

Conference coverage ensures the HD community receives updates before formal publication, translating high-level science into accessible summaries. We also strive to provide those updates in ways that serve the community in how they consume news - immediately with live posting, or later with long-form articles - on our website or across the social media platform of their choice.

#### **D. Direct Community Engagement**

In 2025, HDBuzz engaged directly with families worldwide:

*Live Talks:*

- HDSA National Convention (Indianapolis, USA)
- Huntington Society of Canada National Conference (Niagara Falls, Canada)
- HDYO International Young Adult Congress (Prague, Czech Republic)

*Interactive Engagement:*

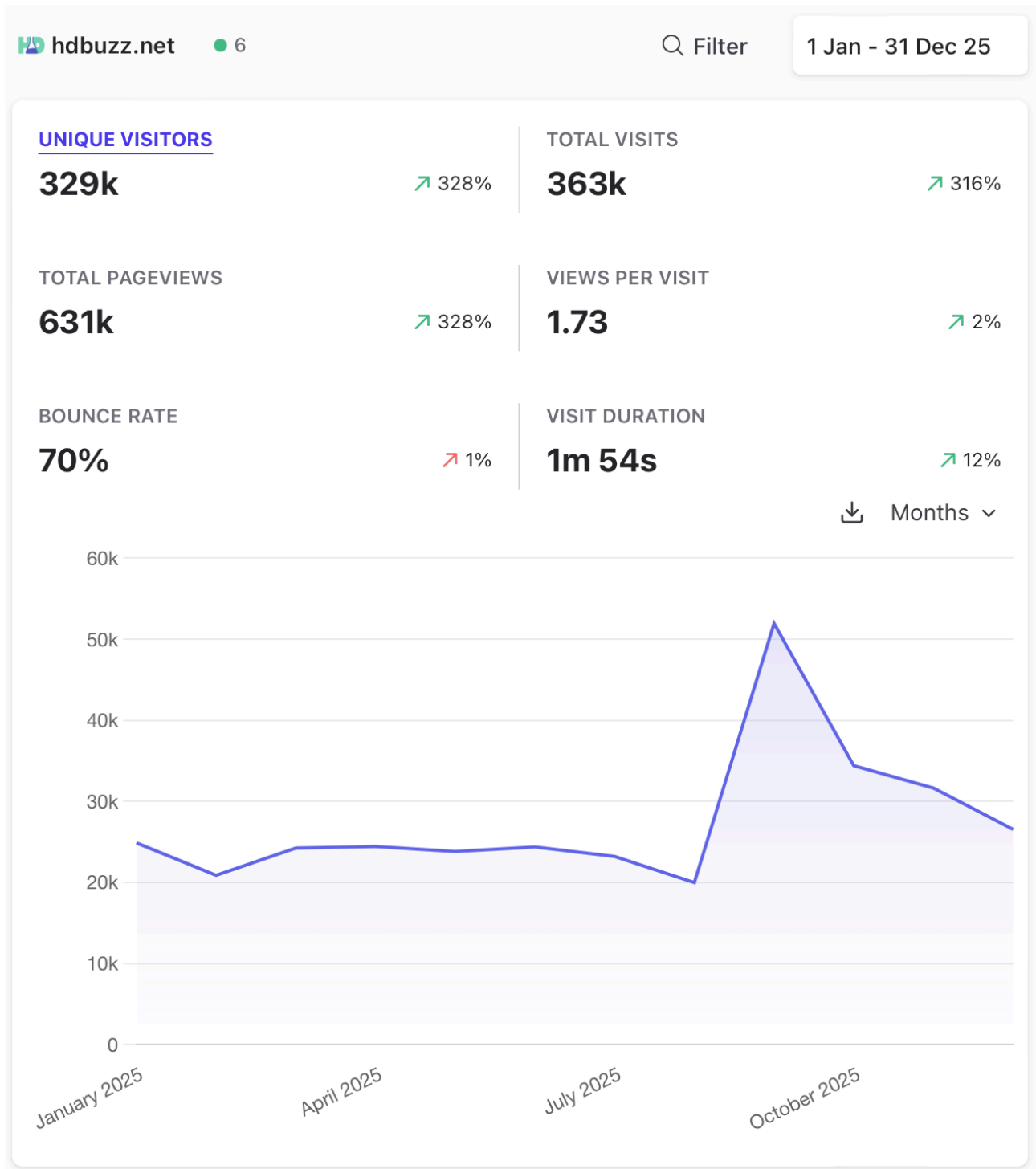
- Live social media takeover for the Huntington's Disease Foundation
- Ask-me-anything webinar with HDSA

These initiatives strengthened two-way dialogue and reinforced trust during a year of major clinical developments.

#### **E. Digital and Platform Expansion**

Our website underwent significant investment:

- Invested in website updates and modernisation, transferring platforms from Rails to WordPress, improving overall functionality and enabling new features to be added.
- Initiated AI translation into 11 languages.
- This ensured global accessibility and relevance across evolving digital ecosystems.
- Our readership for 2025 exceeded 329,000 unique visitors, with more than 630,000 page views
- Email subscriptions now total 4936 readers with an open rate of >40%!



**Figure 2. Statistics for readership on [hdbuzz.net](https://hdbuzz.net) for 2025**

In 2025, HDBuzz grew its social media platforms:

- Expanded our presence on platforms added in 2024 (Instagram - 725 new followers, 1023 followers total; Bluesky - 230 followers total)
- Launched an account on LinkedIn, now with 567 new followers in 2025.



- Maintained our presence on Facebook (1.4k new followers, 8.4k total followers) and X (6.3k followers total).

NB: statistics provided based on availability of analytics on each platform.

## **F. Fundraising and Financial Independence**

*HDBuzz ran two major fundraising campaigns in 2025:*

### Spring: "Hope in Full Bloom"

- Launched ahead of expected Q2 clinical trial results (April 1 - May 27).
- Raised funds for real-time trial coverage.
- Goal: \$30,000 USD; Raised: \$13,066
- Average donation = \$54; Minimum = \$5; Maximum = \$1,000

### Fall: "Falling Into Hope"

- Followed the September AMT-130 announcement and November regulatory setback (Sept 2 - Oct 28).
- Reinforced HDBuzz's role as a steady, unbiased voice during volatility.
- Goal: \$30,000 USD; Raised: \$44,471
- Average donation = \$54 (less max); Minimum = \$5; Maximum = \$25,000 (2nd highest, \$2,000)

### Funds supported:

- Website maintenance
- Website updates
- Translation
- Writer/editor time
- Mentorship programs
- Social media expansion

### HDBuzz remains firmly committed to:

- No paywalls
- No ads
- No pharmaceutical funding



#### **4. Governance and Compliance**

*2025 governance milestones:*

- Established infrastructure to transition to independent 501(c)(3).
- Formation of advisory board.
  - Hugh Rickards
  - Ray Truant
  - Vanessa Wheeler
  - Jenny Morton
- Reinforcement of conflict-of-interest policies.
- Continued commitment to zero pharmaceutical funding.

As disease-modifying therapies approach regulatory milestones, governance integrity is mission-critical.



## **5. Strategic Initiatives and Future Goals (2026+)**

- Maintain twice-weekly publication schedule.
- Expand mentorship and formalise science communication training.
- Offload writing/editing time commitment.
- Begin applying for journalism-based grants.
- Formalize fundraising strategy.
- Increase recurring donor base to achieve sustainability threshold.
- Deepen social media and digital engagement.
- Continue proactive misinformation mitigation.
- Expand global representation in authorship and coverage.



## 6. Challenges and Risks

### **Funding Stability:**

HDBuzz operates on a community-supported funding model and does not accept pharmaceutical funding. This structure preserves independence but requires sustained donor engagement and recurring contributions to maintain operational stability. Variability in annual giving could impact publication cadence, conference presence, translation capacity, and mentorship programs.

HDBuzz is strengthening financial resilience through diversified fundraising campaigns (e.g., Spring and Fall campaigns), clear sustainability messaging (e.g., 5% of readers giving \$20/month model), expansion of individual donor pipelines, alternative funding mechanisms (e.g., journalism grants), and continued transparency about how funds directly support operations. Transition to independent 501(c)(3) status and establishment of formal governance structures further enhance donor confidence and long-term sustainability.

### **Rapid Therapeutic Evolution:**

As disease-modifying therapies move through clinical development, regulatory decisions and trial results may shift unexpectedly (e.g., AMT-130 developments in 2025). Rapid changes can create confusion, emotional volatility within the community, and reputational risk if reporting is perceived as incomplete or biased.

HDBuzz maintains strict editorial independence, avoids pharmaceutical funding, and prioritises balanced, evidence-based interpretation of emerging data. Real-time conference reporting, careful contextualisation of preliminary findings, and transparent discussion of limitations help ensure the community receives accurate, measured analysis during both hopeful and disappointing developments.

### **Information Ecosystem Volatility:**

Social media platforms accelerate the spread of misinformation, overinterpretation of early data, and hype cycles around unproven therapies. This can undermine trust, distort expectations, and place additional pressure on HDBuzz to respond quickly.

HDBuzz expanded its social media presence (Instagram, Bluesky, LinkedIn, Facebook, X) with dedicated management to proactively engage audiences where misinformation spreads. Articles explicitly address emerging misconceptions, and content emphasises scientific nuance, uncertainty, and risk-benefit balance. Continued investment in accessible science communication serves as a stabilising counterweight to hype cycles.

### **Operational Capacity:**



Increasing output to a bi-weekly publication schedule significantly increases editorial workload, coordination demands, and contributor time commitments. Sustained high output without structured support risks burnout, reduced quality control, or inconsistent publication schedules.

HDBuzz expanded its writing team and launched mentorship pipelines (HDBuzz Prize and HD-CAG partnerships). Continued development of early-career contributors builds long-term operational resilience. In 2026, we propose bringing on an editorial manager. The inclusion of this role will significantly offload writing/editing commitments to free up time for leadership to focus on day-to-day operations. Strategic planning ensures that publication frequency keeps pace with the accelerating volume of HD research and the community's need for timely, accurate interpretation.



## 7. Financial Overview & Budget

HDBuzz remains in strong financial standing as an independent 501(c)(3) nonprofit with no debts or liabilities.

### 2025 Summary:

- Total revenue: \$163,032 USD (up from \$57,830 in 2024)
- Total expenses: \$131,040 USD (up from \$42,986 in 2024)
- Year-end carryover: \$48,753 USD (up from \$17,181 in 2024)

Our 2025 revenue came from foundation grants (HDF, HSC, HSG, Griffin Foundation, Michael Berman Family Foundation, Foundation of the Swiss Huntington's Disease Society), major individual donors, and reader contributions from our donation button.

		<b>2025</b>
<b>REVENUE (USD)</b>		
<i>Category</i>	<i>Name</i>	
Foundation donations		70,277.35
Individual donors		40,812.76
Other		51,942.08
<b>Total Revenues</b>		<b>163,032.19</b>
<b>YoY carryover</b>		<b>17,180.65</b>
<b>Total Revenues</b>		<b>180,212.84</b>
<b>EXPENDITURES (USD)</b>		
<i>Category</i>	<i>Subcategory</i>	
FIXED		
	Writer stipends, editorial staff, & leadership	86,200.00
	Website & technology	26,160.61
	Social media and promotion	8,885.37
	Legal & administrative	10,214.31
	Conferences & travel	
<b>Total Expenditures</b>		<b>131,460.29</b>
<b>FUNDS CARRIED FORWARD</b>		<b>48,752.55</b>

Figure 5. 2025 budget pulled February 13, 2025.



## **7. Acknowledgements**

HDBuzz's accomplishments in 2025 were made possible by the dedication and generosity of a remarkable community. We are deeply grateful to our writers, editors, and scientific reviewers who generously contributed their expertise to ensure accuracy, clarity, and integrity in every article. We thank the Huntington's Disease Foundation for sponsoring the HDBuzz Prize for Young Science Writers and for partnering with us on the HD-CAG mentorship initiative, helping to cultivate the next generation of HD researchers and communicators. We also acknowledge the organisers of major scientific and community conferences, including CHDI, the Huntington Study Group, HDSA, HDYO, and the Huntington Society of Canada, for providing platforms that enable timely reporting and direct engagement with families. Our advisory board has provided essential governance and strategic guidance during this transformative year of independence. We are especially grateful to our Board of Directors for their thoughtful governance, strategic oversight, and steadfast commitment to safeguarding HDBuzz's independence during this pivotal year of growth and transition. Most importantly, we thank the global Huntington's disease community, including the families, clinicians, researchers, advocates, and individual donors, whose trust, readership, and financial support sustain HDBuzz's mission of delivering independent, accessible, and unbiased HD research news.