# Real-World Patterns of On-Demand Therapy Utilization Following Initiation of Long-Term Prophylaxis in Hereditary Angioedema

Prime THERAPEUTICS™

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## Background

- Hereditary angioedema (HAE) is a rare genetic disorder associated with recurrent severe edema attacks involving the skin and mucosa.
- Guidelines recommend treating HAE attacks with on-demand therapy (ODT) and individualizing long-term prophylaxis (LTP) initiation based on disease activity, burden, and patient preference.[1]
- HAE can result in annual total care costs exceeding $1M per member, with roughly 97% attributable to drug costs.[2]
- However, real-world evidence on how initiation patterns and LTP influences ODT use and costs remains limited.[3]

## Objective

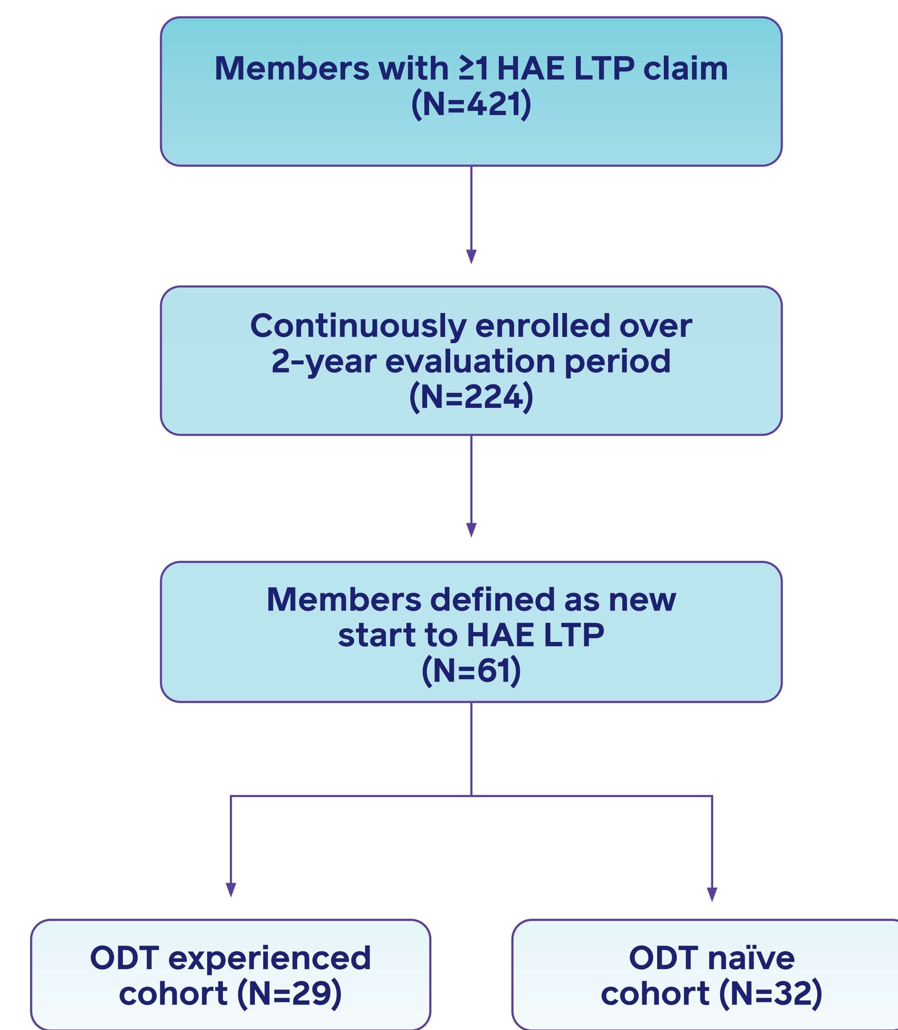
Our objective is to evaluate real-world ODT patterns and costs following LTP initiation in members with HAE.

## Methods

- This was a retrospective analysis of medical and pharmacy claims from a commercial database of 17 million lives across the United States.
- Claims were queried to identify members' first HAE index LTP (C1-esterase agents, berotralstat, lanadelumab) between January 2023 and September 2024.
- Inclusion criteria: Members with continuous enrollment 12 months leading up to (pre-LTP period) and persisting after (post-LTP period) their index date, no pre-index LTP claims, and at least 1 LTP claim in the post-LTP period.
- Drug costs were calculated using ODT (non-LTP C1-esterase agents, icatibant, ecallantide) and LTP allowed amounts.
- ODT utilization was estimated by converting total clinical units dispensed into the approximate number of HAE attacks. Attack counts were calculated by dividing total units by the minimum labeled dose per attack for each product: Berinert (1,500 IU), Firazyr (30 mg), Kalbitor (30 mg), and Ruconest (2,100 IU).

## Figure 1

Study Population




HAE = hereditary angioedema; LTP = long-term prophylaxis; ODT = on-demand therapy

## Figure 2

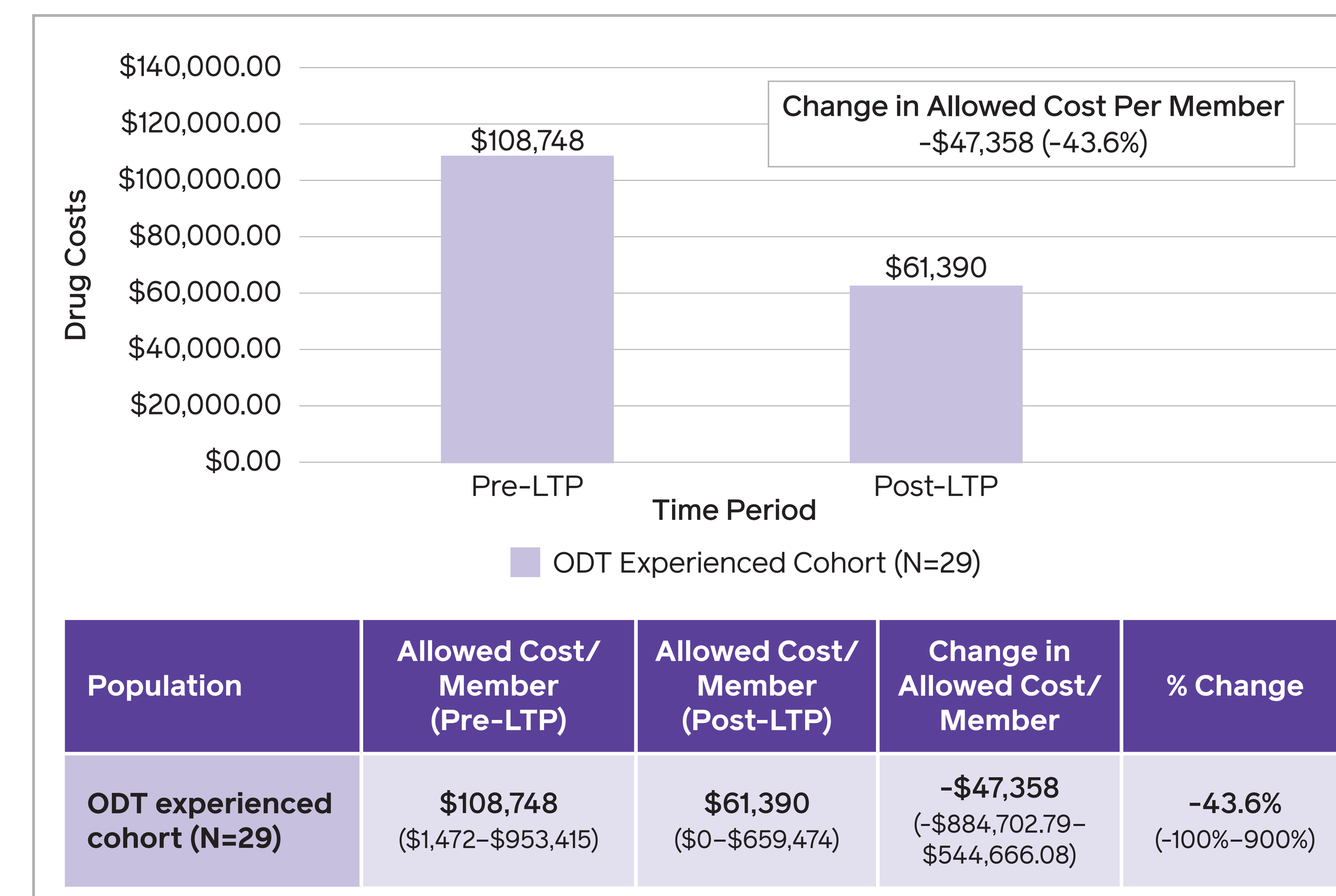
Overview of On-Demand Therapy Utilization After Long-Term Prophylaxis Initiation

| ODT Utilization After LTP Initiation | |
|---|---|
| Members With Reduction | 65.5% (n=19) |
| Members With No Change | 10.3% (n=3) |
| Members With Increase | 24.1% (n=7) |

ODT = on-demand therapy; LTP = long-term prophylaxis

## Figure 3

On-Demand Therapy Annualized Cost Per Member Before and After Long-Term Prophylaxis Initiation




| Population | Allowed Cost/ Member (Pre-LTP) | Allowed Cost/ Member (Post-LTP) | Change in Allowed Cost/ Member | % Change |
|---|---|---|---|---|
| ODT experienced cohort (N=29) | $108,748 ($1,472–$953,415) | $61,390 ($0–$659,474) | -$47,358 (-$884,702.79–$544,666.08) | -43.6% (-100%–900%) |

ODT = on-demand therapy; LTP = long-term prophylaxis

## Results

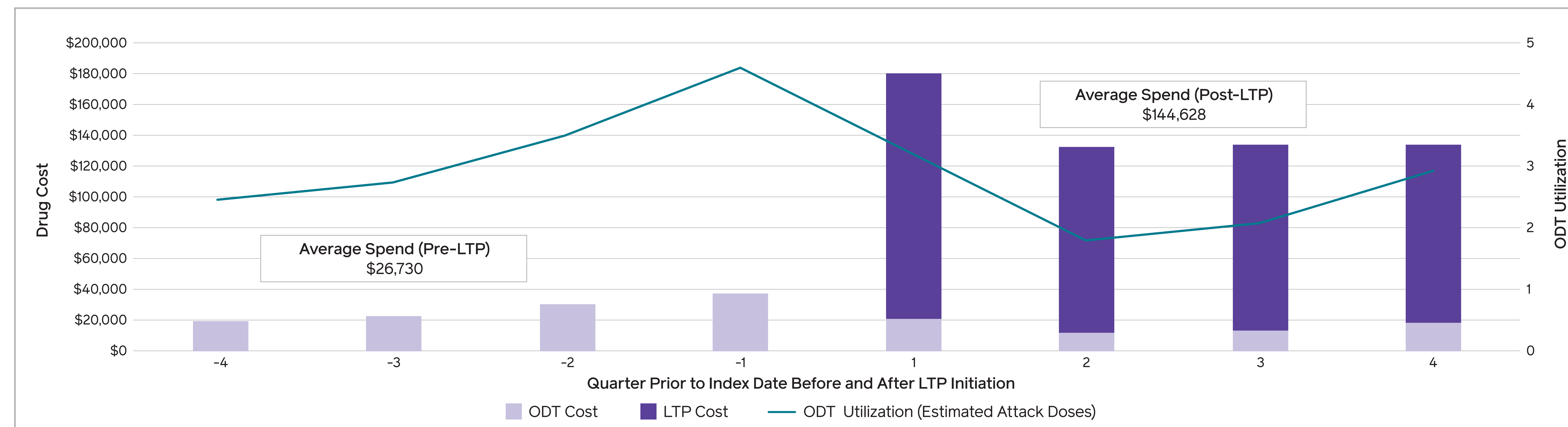
- Among 61 members initiated on LTP for HAE, 52.5% (n=32) started LTP without prior ODT while 47.5% (n=29) previously received ODT.
- In the ODT-experienced subgroup, 65.5% (n=19) experienced a reduction in ODT utilization after LTP initiation, 10.3% (n=3) had no change, and 24.1% (n=7) showed an increase.
- Overall, ODT spend in this subgroup declined by $1.37M, averaging a $47,358 reduction per member.
- Members with reduced ODT use had an average cost decrease of $114K, while those with increased ODT use had an average cost increase of $112K; both groups averaged 4 ODT claims per member.
- After starting LTP, the average ODT utilization per member decreased from 13.6 to 9.7, a 29% reduction.

## Limitations

- Limited visibility into clinical outcomes, including hospitalizations, attack frequency, and patient-reported measures—such as stockpiling and nonadherence—restricts interpretation of clinical impact. Drugs purchased via patient assistance programs and cash are not included in paid-claims data.
- The 12-month follow-up period may not fully capture long-term stabilization or delayed therapeutic response to LTP; longer observation could provide a more complete view of utilization trends.
- Real-world claims data may not fully reflect all on-demand HAE treatment activity, such as infrequent attacks or earlier untreated episodes, potentially influencing the observed proportion of patients initiating LTP without documented prior ODT use.
- The study population was limited to commercially insured members; findings may not be generalizable to Medicare and Medicaid populations.
- Administrative pharmacy and medical claims have the potential to be miscoded and include assumptions of members' actual drug use.

## Figure 4

On-Demand Therapy Experienced Cohort—Average Drug Cost and On-Demand Therapy Utilization Before and After Long-Term Prophylaxis Initiation




ODT = on-demand therapy; LTP = long-term prophylaxis

## Conclusions

- Over half of the members initiated LTP without prior ODT, indicating variability in treatment patterns among HAE members.
- For most members with prior ODT use, LTP initiation reduced ODT utilization and costs, suggesting the expected impact of dispensed LTP treatment on reducing ODT need.
- Despite a more than 5-fold increase in medication costs with the initiation of LTP, over one-third of members continued to require ODT without reduction. As guidelines recommend treating all attacks and achieving total disease control to normalize patients' lives, these results suggest that many members may experience ongoing breakthrough attacks, leading to persistent disease burden and complex treatment regimens. These findings highlight the potential need for targeted drug management strategies and case management interventions to optimize cost-effective HAE care.

## References

1. Maurer M, Magerl M, Betschel S, et al. The international WAO/EAACI guideline for the management of hereditary angioedema—The 2021 revision and update. *Allergy.* 2022;77(7):1961-1990. doi:10.1111/all.15214
2. Vande Walle SE, Starner CI, Gleason PP. Hereditary angioedema: A comprehensive integrated medical and pharmacy claims analysis of utilization and costs among 15 million commercially insured members. Presented at: Academy of Managed Care Pharmacy (AMCP) Annual Meeting; April 23-26, 2018; Boston, MA.
3. Tachdjian R, Nenci C, Katkade V, et al. Real-world analysis of treatment patterns among patients with hereditary angioedema in the United States. *J Allergy Clin Immunol.* 2025;155(2):AB431. doi:10.1016/j.jaci.2024.12.986

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