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# Public Comment By Steven LePage

### **Public Comment on HR32: Genetic Testing and Its Implications**

I would like to express my concerns regarding the vagueness and lack of transparency surrounding HR32. After some research, including an interview with Rep. Ramone and Rep. Hilovsky, and additional materials from the SEBC website, I've pieced together that the core of the proposal focuses on genetic testing or DNA mapping. The technology being promoted appears to involve Inside Tracker, a company specializing in genetic testing.

While I acknowledge that advancements in genetic testing could potentially lead to improved healthcare outcomes, I am highly skeptical of claims that this technology will lower healthcare costs for the State of Delaware. Historically, hospitals and healthcare systems have not willingly sacrificed revenue. Rather than a decrease in costs, I foresee a shift in focus from volume-based care to high-margin, specialized services. This shift would allow hospitals to recoup revenue lost elsewhere, effectively nullifying any promised cost savings.

Does anyone genuinely believe that healthcare providers are willing to voluntarily reduce their revenue?

Based on my experience with Medicare Advantage and what I view as disinformation from the State on that subject, I strongly urge this committee to take a critical, well-rounded approach to the promises being made. We should not simply accept the optimistic sales pitches as we did with Medicare Advantage, which initially seemed like a breakthrough but later revealed significant shortcomings. I urge the committee to examine both the potential benefits and the very real downsides before moving forward.

### **Key Pitfalls to Consider:**

### 1. Privacy Concerns:

- Data Breaches: Genetic data is highly sensitive, and if the company storing this
  information experiences a data breach, it could lead to catastrophic privacy violations.
  Once exposed, this data cannot be reclaimed.
- Unauthorized Use: Even with consent, genetic data could potentially be used for purposes you did not agree to, such as third-party research, marketing, or even law enforcement investigations.

### 2. Discrimination:

- Health Insurance: Risks that genetic information could be used against individuals by insurers, particularly when it comes to life or long-term care insurance.
- Car Insurance: Insurers could theoretically use genetic information to predict susceptibility to certain health conditions (e.g., vision impairments, reaction times) that may increase the likelihood of car accidents.
- Home Insurance: Genetic predispositions to certain diseases or disabilities could influence how insurers assess risks related to home safety (e.g., fall risks, mobility issues that affect home modifications).
- Employment: There is also the concern that employers might use genetic information to influence hiring, promotions, or workplace benefits, which could create unfair biases in the workforce.

### 3. Impact on Family Members:

Revealing Family Secrets: Genetic testing can unveil unexpected family relationships,
 such as unknown paternity or adoption, which could cause emotional distress.

Implications for Relatives: Your genetic test results could affect relatives who may not
wish to know their genetic risks or be included in a genetic database. This is an ethical
issue that is often overlooked.

### 4. Legal Issues:

- Forensic Use: Your DNA data could be used in criminal investigations. While this might sound like a positive use, it could lead to unintended consequences, such as implicating relatives who share your genetic markers.
- Future Legal Changes: As laws evolve, the regulations surrounding the use of genetic data may change. What seems permissible today could become a liability tomorrow.

### 5. Permanence of Data:

 Inability to Retract: Once your DNA is provided, retracting that information is nearly impossible. Even if you request deletion, copies or derived data may continue to exist in databases beyond your control.

### 6. Misinterpretation of Results:

- Psychological Impact: Misunderstanding or overinterpreting genetic test results could lead to unnecessary fear, anxiety, or emotional distress. A predisposition does not guarantee a condition will develop, and individuals may not be equipped to process such information accurately.
- Incomplete Picture: Genetic testing alone does not provide a complete assessment of one's health, as environmental factors and lifestyle choices play critical roles in overall well-being.

### 7. Commercial Exploitation:

 Profit Motive: Companies might use your genetic data for product development without compensating you. Additionally, your data could be sold to third parties for marketing, research, or other purposes beyond your control.

### 8. Ethical Concerns:

- o **Informed Consent:** There are often gaps in the consent process, particularly when it comes to how data will be used in the future. Individuals may not fully grasp the long-term implications of sharing their genetic information.
- Social Inequities: Certain groups could be disproportionately represented in genetic studies, exacerbating existing health disparities and social inequalities.

### 9. Potential for Governmental Overreach:

Regulatory and Oversight Concerns: If governments begin to rely more heavily on genetic data in public programs (e.g., public health campaigns or healthcare regulation), robust oversight is essential to ensure that the use of this data remains ethical and non-intrusive. It's important that any expansion of genetic data use in government settings be guided by clear, transparent policies that prioritize privacy and individual rights, ensuring that people are fully aware of how their data is being used and protected.

Before Delaware embraces this technology, I urge the committee to carefully consider the full scope of implications, including potential costs, privacy risks, and unintended consequences. While genetic testing may offer promising healthcare insights, we must not ignore the significant pitfalls that come with commercial DNA testing. A thorough and transparent evaluation is essential to ensure we are not overlooking the downsides of such initiatives.

Please provide this to all of the committee members

Thank you for your time and consideration.

Very Respectfully,
Steven LePage
Persian Gulf War Veteran - Desert Shield/Desert Storm
USAF, Retired
State of Delaware, Department of Technology and Information, Retired

# Public Comment By Tom Pledgie

### Public Comments to SEBC September 23, 2024

### **Dear Members of the SEBC:**

Brian Stitzel from WTW at last Monday's SEBC Subcommittee Meeting presented the chart below to better flesh out the impact of the 27% premium rate increase on Medicare Retirees who have retired since 2012. On Brian's chart last month that I shared with you, it showed a \$34million FY25 Surplus. That was \$34million for just 6 months. We can now see that the amount of Premium Overcharge starting in FY25 through FY28 totals at least \$110.4million. Looks like with a 0% rate increase,

There is NO NEED for any Premium increase for Medicare Retirees until at least FY29!

	Rate Increase	27.0%	0.0%	0.0%	0.0%
	FY24	FY25	FY26	FY27	FY28
GHIP Costs (\$ millions)	Projected	Projected	Projected	Projected	Projected
GHIP Revenues					
Premium Contributions	\$166.0	\$192.1	\$221.2	\$223.4	\$225.6
Transfer from OMB					
Payback of Transfer from OMB					
Other Revenues	\$125.3	\$153.1	\$171.3	\$184.6	\$194.0
Total Operating Revenues	\$291.3	\$345.2	\$392.5	\$408.0	\$419.6
GHIP Expenses					
Claims	\$271.7	\$300.7	\$330.8	\$362.7	\$396.3
Expenses	\$10.9	\$11.6	\$11.7	\$12.2	\$12.6
Total Operating Expenses	\$282.5	\$312.3	\$342.5	\$374.9	\$408.9
% Change Per Member					
Adjusted Net Income	\$8.8	\$32.9	\$50.0	\$33.1	\$10.7
Balance Forward	\$0.0	\$0.1	\$33.0	\$83.0	\$116.1
Ending Fund Cash Balance	\$0.1	\$33.0	\$83.0	\$116.1	\$126.8
- Less Claims Liability	\$0.0	\$0.0	\$0.0	\$0.0	\$0.0
- Less Minimum Reserve	\$6.0	\$6.8	\$13.7	\$15.0	\$16.4
GHIP Surplus (After Reserves/Deposits)	(\$5.9)	\$26.2	\$69.3	\$101.1	\$110.4

Brian also presented the following chart to demonstrate the impact of his proposed 4.4% annual/compounded Premium increase across Retiree groups so that by FY28 the claims vs premiums (or GHIP Surplus) would equal "0"—see bottom right-hand corner.

Long-term Projection - All GHIP Groups Combined

	Rate Increase	27.0%	4.4%	4.4%	4.4%	Assumptions:			
GHIP Costs (\$ millions)	FY24	FY25	FY26	FY27	FY28	<ul> <li>8% medical trend, 5% Medicfill trend,</li> </ul>			
	Projected	Projected	Projected	Projected	Projected	see Appendix for graded pharmacy trend assumption			
Average Enrolled Members	133,487	136,122	137,484	138,858	140,247	<ul> <li>Starting with actual July, 2024 open</li> </ul>			
GHIP Revenues						enrollment results and 1% per annum			
Premium Contributions - Non-Medicare	\$824.0	\$1,067.4	\$1,136.8	\$1,199.2	\$1,264.9	growth in GHIP membership with			
Premium Contributions - Medicare	\$166.0	\$192.1	\$225.3	\$237.7	\$250.7	consistent plan and tier elections			
Total Premium Contributions	\$990.0	\$1,259.5	\$1,362.1	\$1,436.8	\$1,515.6	thereafter			
Transfer from OMB	\$7.3					<ul> <li>Reflects added cost for legislation going into effect during FY25</li> </ul>			
Payback of Transfer from OMB	, .								
Other Revenues	\$223.2	\$273.0	\$311.0	\$339.3	\$363.4	<ul> <li>Reflects current market check improvements for FY25/FY26</li> </ul>			
Total Operating Revenues	\$1,220.5	\$1,525.2	\$1,673.1	\$1,776.1	\$1,879.0	pharmacy program			
GHIP Expenses						Reflect changes to 2025 (and beyond)			
Claims	\$1,230.7	\$1,407.8	\$1,560.6	\$1,714.4	\$1,875.9	EGWP reimbursements due to the			
Expenses	\$48.6	\$52.6	\$52.9	\$54.9	\$57.1	Inflation Reduction Act			
Total Operating Expenses	\$1,279.3	\$1,460.4	\$1,613.5	\$1,769.3	\$1,933.0	<ul> <li>Reflects increased cost due to plan</li> </ul>			
% Change Per Member	5.4%	12.2%	9.8%	8.8%	8.3%	changes adopted for FY25 to be in			
Adjusted Net Income	(\$58.7)	\$64.8	\$59.6	\$6.8	(\$54.0)				
Balance Forward	\$58.8	\$0.1	\$64.9	\$124.5	\$131.3	<ul> <li>Does not reflect added cost due to</li> </ul>			
Ending Fund Cash Balance	\$0.1	\$64.9	\$124.5	\$131.3	\$77.3	potential pending legislation			
- Less Claims Liability	\$0.0	\$0.0	\$0.0	\$0.0	\$0.0				
- Less Minimum Reserve	\$28.2	\$32.3	\$64.5	\$70.8	\$77.3				
GHIP Surplus (After Peserves/Denosits)	(\$28.1)	\$32.6	\$60.0	\$60.5	/\$n n\				

First, using FY25 as the base year, he is proposing to increase FY26 Premiums by 4.4%, then FY27 compound to 8.8%, and finally FY29 to 13.4%. But if you read his 'Assumptions', it states that 'medical trend' data is at an 8% annual increase, which means that the shortfall is at least 8% in FY26 NOT 4.4%, compounds to 16% in FY27 NOT 8.8%, and then to 24% in FY28 NOT 13.4%.

How do you fix the 8/16/24% shortfall with a 4.4/8.8/13.4% fix? You don't!

You get a crisis just like WTW led us into in FY24/25.

The second problem with his work is that he applies the 4.4% premium rate increase to the Medicare Retirees in FY26, 27, and 28. This is on top of the \$110million Premium Overcharge sited above. It will increase the Overcharge for Medicare Retirees to \$158million. This is a charge on Retirees who are ages 65-77 who have been retired for several years living on basically fixed State Pensions plus Social Security.

Why increase the Premium OVERCHARGE even more???

Medicare Retirees claims are NOT causing any kind of shortfall through at least FY29. BUT they are being OVERCHARGED \$150million of Premiums over the next 3 years by Brian's plan.

Should not the decision that overcharges one group of Retirees and undercharges another be made by the SEBC after open discussion in public and NOT by a 'bean counter'???

## Public Comment By Bob Clarkin

## PUBLIC COMMENTS FOR THE 9/23/24 SEBC MEETING - SUBMITTED BY ROBERT CLARKIN, 9/20/24

Please accept my public comments in support of the comments submitted by Steve LePage regarding HR32 and the implications of genetic testing.

During the 9/16/24 meeting of the SEBC Health Policy and Planning Subcommittee, the Statewide Benefits Office presented a slide show titled "GHIP Diabetes Management and Prevention Programs and Resources". The same presentation is included in the materials for the 9/23/24 SEBC meeting.

Section 4 of the presentation titled "Programs and Resources Under Consideration by the Statewide Benefits Office" reads: "The Statewide Benefits Office (SBO) continues to research and evaluate potential programs to offer Group Health Insurance Plan (GHIP) members to enhance members benefits, improve quality of life and provide savings to the member and the plan by ensuring the proper management of diabetes and prevention of diabetes when able. Below is a summary of benefit programs the SBO has evaluated this year and is actively considering for implementation......"

"Inside Tracker - Created by experts in the fields of aging, genetics, and biometric data, InsideTracker provides a personal health analysis and data-driven wellness guide, designed to help you live healthier longer. By analyzing your body's biomarkers, InsideTracker provides an objective health assessment along with a custom set of actionable recommendations and insights for your nutrition, supplements, exercise, and lifestyle. Integrated within an intuitive mobile app, InsideTracker reveals your personalized path to improving your health and longevity from the inside out."

Inside Tracker offers a number of options to create its "wellness guide". Many of the options utilize a blood sample to identify and analyze up to 48 biomarkers. An additional option uses an individuals DNA to identify and analyze 261 DNA markers. Use of an individuals DNA to create a "wellness guide" is where Steve's concerns come into play. I will not repeat Steve's concerns here, but I would like to strongly encourage members of the SEBC to take his concerns under advisement when discussions of products that utilize an individuals DNA are considered as a "diabetes management prevention program or resource".

I would also like to bring to the Committees attention Delaware Code, Title 16, Chapter 12, Informed Consent and Confidentiality, Subchapter 1, Genetic Information, Sections 1201-1208 to use as guidance when considering any prevention program product that requires the collection, analysis, and storage of genetic information.