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**Statement on behalf of the  
American Civil Liberties Union of the District of Columbia  
before the D.C. Council Committee on Health  
Hearing on Bill 25-0930 – “Consumer Health Information Privacy  
Protection Act (CHIPPA) of 2024”  
by  
Scarlett Aldebot, Policy Advocacy Director  
October 17, 2024**

Good morning, Chair Henderson and members of the Committee. I am Scarlett Aldebot, Policy Advocacy Director at the American Civil Liberties Union of the District of Columbia (ACLU-D.C.). On behalf of our over 14,000 members in all 8 wards, ACLU-D.C. submits the following written testimony supporting Bill 25-0930, the Consumer Health Information Privacy Protection Act of 2024 (CHIPPA).

ACLU-D.C. supports this legislation and urges the Committee to move it forward. CHIPPA provides critical protection against the misuse, without knowledge or consent, of our personal health data collected by entities that are not covered by the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA). There are wide ranging reasons for valuing the protection of our health information. Beyond basic notions of choice, individual rights, and privacy from intrusion, health information is in urgent need of protection because it provides insight into some of the most closely held details about our personhood and lives. These details, unknowingly collected, stored, or ill-used, could result in health discrimination, economic harm, and stigma. Individuals, therefore, should be able to know about and affirmatively consent to the uses of this especially sensitive type of information.

Individuals are generally aware of the fact that federal law protects some health information, but many are not aware that this protection only extends to health information shared with entities covered under HIPAA – namely healthcare providers, healthcare plans, and similar entities. While individuals in the past shared health information with a relatively small number of entities, many of which were covered by HIPAA, individuals today often share personal health data with non-covered entities much more frequently, such as fitness apps, period and health trackers, and location data revealing our visits to healthcare clinics. Often, once individuals have shared this information, they do not have a meaningful opportunity to consent to whether that information is further shared with third parties or to how that information will be used, including in ways that the consumer might not have contemplated when providing the information in the first place.

CHIPPA would require regulated entities to establish and make publicly available a consumer health data privacy policy governing the collection, use, sharing, and sale of consumer health data. CHIPPA would also require companies to limit their use of health information to what individuals expect and to obtain their informed and affirmative consent before sharing their personal health data. It would create a right for individuals to access and choose the ways in which their personal health data is used by CHIPPA-covered entities. Under CHIPPA, individuals could obtain access to collected health data, withdraw consent for use of that data, and could request deletion of their health data. CHIPPA would also require valid consumer authorization specifically before an entity could sell their data. Under CHIPPA, a business providing a consumer with a fitness application, for example, would have to provide the consumer with the right to know what, why, how, and to whom their data is being given and the consumer would have the right to affirmatively consent to that action and to also withdraw that consent.

Finally, CHIPPA establishes that regulated entities can only collect health data that is necessary for the purposes disclosed to individuals and makes violations unfair and deceptive trade practices. CHIPPA creates a private right of action for violations of the law so that individuals whose rights have been violated can directly seek redress; this builds in an additional incentive for businesses to follow the law and preserves local resources.

Privacy laws serve as vital guardrails of personal information in an increasingly interconnected world. ACLU-D.C. recognizes the paramount importance of privacy, and we firmly believe that transparency and accountability are necessary to protect our rights to privacy. CHIPPA would protect people in D.C. against the unauthorized and harmful use of personal consumer health data by providing comprehensive privacy protections for consumer data that consumers share with non-HIPAA covered entities. CHIPPA is important for all consumers in D.C., but it is especially important for consumers who are particularly vulnerable to non-consensual disclosure of their private health information, including LGBTQ+ people and individuals seeking reproductive health services. The ACLU-D.C. thanks the Committee for the opportunity to submit written testimony today. We once again urge the Committee to pass this legislation that would safeguard critical consumer health data for every D.C. resident and significantly reduce the likelihood that anyone's sensitive health information ends up in the wrong hands.