Take Two

The day when the FDA finally gave the nod to DHPG and pentamidine, HIVers could breathe a sigh of relief.

May 1, 2000 By Carl George

First found my way to the PWA Health Group in 1986 because a friend in Toronto called and asked me to buy whatever they had—didn't matter what, he said just buy it. Dozens of people were waiting in line for frozen egg lipids from Israel that tasted terrible and a 40-pill combination of German enzymes that had to be taken twice a day and caused awful upset stomach and flatulence. They didn't work, but with more-viable drugs mired in FDA red tape, there was nothing else.

The death toll was rising fast— friends, acquaintances, famous people—and still no drugs. PWAs tried anything from quack remedies, untested treatments to slow the virus and assuage the desperation. People were dying sometimes only weeks after diagnosis. Usually Pneumocystis carinii pneumonia (PCP) did it, filling the lungs with fluid and drowning them. Those who escaped PCP might live long enough to go blind when cytomegalovirus (CMV) spread into their retinas. We were all terrified.

Finally on May 2, 1989, after a four-year community push, PWAs testimony before Congress and a barrage of demos, two drugs were recommended for approval by an FDA advisory group: aerosol pentamidine to treat or prevent PCP, and DHPG (Gancyclovir) for CMV. Neither drug was fun. Pentamidine required you to breathe the aerosolized drug through a mask for anywhere from 20 minutes to an hour. It was very harsh and left a persistent, distinctly metallic taste in the mouth, but it worked. DHPG was even worse, requiring daily direct injections, "infusaports" if your veins were too thin or a Hickman catheter permanently embedded in the chest. No picnic. But we finally had the drugs—PWAs could use them, pushing blindness away, cheating death for a time and bringing hope into our lives.
